



## The Challenge of Gaining Access to Informal Caregivers in the AdvancedHeart Failure Population in Ireland

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# EAPC 2015

14<sup>th</sup> World Congress of the European  
Association for Palliative Care

## Building Bridges

8 – 10 May 2015  
Copenhagen, Denmark



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14<sup>th</sup> World Congress of the European Association for Palliative Care (EAPC)  
Copenhagen, Denmark, 10 May 2015

## **Abstracts**

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Dear Congress participant,

### Welcome to the EAPC World Congress in Copenhagen!

This Congress has adopted the motto of 'building bridges' and this is reflected in the spectacular images of beautifully designed bridges connecting the islands and mainland of Denmark, and across the sea to Sweden. The metaphor for bridges works well for the connections that we hope you will make during the Congress, perhaps to new people, teams and ideas. Palliative care is a multidisciplinary enterprise and we can gain much by our willingness to build bridges to those working in other health care areas.

The well-known song released by Paul Simon and Art Garfunkel on 26th January 1970 called 'Bridge over Troubled Water', has, to me, a special resonance with what we aspire to achieve in palliative care. It paints a picture of the importance of acknowledging the physical and psychological state of the person and being with them in their time of need:

*'When you are weary, feeling small  
When tears are in your eyes,  
I will dry them all  
I am on your side  
When times get rough'*

It offers hope that palliative care will embrace all aspects of suffering, including pain management:

*'When evening falls so hard  
I will comfort you  
I'll take your part  
When darkness comes  
And pain is all around'*

The song ends on a positive note with the promise: *'I will ease your mind'*. This reminds us that palliative care is about helping to ease suffering in its broadest sense.

At the Congress, we will be reporting the outcomes of the Prague Charter which was launched at the EAPC World Congress in Prague as a joint action advocating for palliative care as a human right. This built upon previous EAPC initiatives such as Budapest Commitments and the Lisbon Challenge. We welcome you to join with us in an international united effort to improve access to high quality palliative care.



#### **Professor Sheila Payne**

President of the European Association for Palliative Care

#### **Acknowledgements**

I want to offer special thanks to Professor Irene Higginson and Professor Carlo Leget who have co-chaired the Scientific Committee and also acknowledge the important contribution of the members of the scientific committee. Grateful thanks are due to Fiona Wong who has worked closely with Professor Higginson. I am indebted to our international advisory board that have provided detailed and insightful reviews on all the proffered abstracts. For the first time we have obtained three independent reviews for each abstract. Special thanks go to Professor Per Sjoegren, Marlene Sandvad and the local organizing committee for their commitment to ensuring the success of this Congress. As always, the EAPC Head Office team, Heidi Blumhuber, Amelia Giordano and Dr Julie Ling have supported the Congress. Thank you to our efficient and hard working congress organisers, Interplan.

## Dear Congress participant

It is a pleasure to welcome you to the 14th World Congress of the EAPC in Copenhagen. Palliative care practice is complex, challenging and developing rapidly in response to escalating international need. Its success depends on building bridges between different professional and non-professional groups, disciplines, cultures, regions and continents. The theme of the 14th World Congress therefore is 'building bridges'.

With this theme, the EAPC also continues to strive for better access to palliative care for all those who need it, across the globe. To bridge the gap between suffering and palliative care the EAPC launched, in Prague 2013, a petition to urge governments to relieve suffering and ensure the right to palliative care [https://secure.avaaz.org/en/petition/The\\_Prague\\_Charter\\_Relieving\\_suffering](https://secure.avaaz.org/en/petition/The_Prague_Charter_Relieving_suffering). This petition has been signed by more than 7,500 people, and we hope that this number can be increased further during this congress! Please sign if you have not already done so, and encourage your colleagues to do so.

In this 2015 EAPC World Congress we seek to assemble the most skilled and knowledgeable caregivers, clinicians, researchers and educators in the field of palliative care, along with the vibrant opportunities to meet friends, colleagues and experts, and gain new ideas and insights on how to improve care for patients and their families. Due to the geographic position of Copenhagen, bridging Scandinavia with central Europe, as well as the growing interest in palliative care, this conference brings together more than 3,000 participants from a wealth of professional and cultural backgrounds. We are delighted to be able to offer a programme mixing world-leading plenary speakers, early career researchers, clinical and academic experts, and hundreds of cutting edge presentations and posters. Over 1,200 abstracts were submitted for the scientific programme of this conference, the highest ever for an EAPC congress. We were delighted with the quality of submissions, and send our congratulations to all those accepted. Our patients and families deserve the very best in evidence-based practice, underpinned by high quality research, knowledge generation, innovation, education, skilled care and appropriate health and social care policies. We hope that this congress will help all those participating to further advance the field and their own practice or field of study.

Copenhagen – this premier capital of Northern Europe – offers an enchanting environment – with its mixture of old maritime charm and network of parks, public squares and green spaces. Since the completion of the Øresund Bridge, the metropolitan area of Copenhagen has become increasingly integrated with the Swedish province of Scania and its largest city, Malmö, known as the Øresund Region. With bridges connecting the various districts, the cityscape is characterised by parks, promenades and waterfronts. The city is one of Europe's oldest capitals with a royal touch – the monarchy in Denmark is the oldest in the world! Therefore we are very proud that HRH Crown Princess Mary of Denmark, in her kindness, is not only patron of the congress, but will also bestow the honour of a Royal visit on us during the opening ceremony.

We are looking forward to meeting you during the congress!



**Per Sjögren**

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**Irene J Higginson**

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**Carlo Leget**

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## PL1 – Building bridges in palliative care: to where and to whom?

# Building bridges in palliative care: to where and to whom?

**Deliens L.**<sup>1,2</sup>

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<sup>2</sup>Ghent University, End-of-Life Care Research Group, Gent, Belgium

The development of palliative care globally has adapted this concept of 'building bridges' to describe a range of efforts to expand palliative care implementation at local, national and international levels. One of the first clinical bridges built in palliative care was the one from people with cancer towards people with non-cancer diseases, and in frail elderly people. Research bridges were also built from medical and nursing research towards public health research and social sciences. There is a need for more bridges to be built in both clinical and scientific settings, in order to further advance palliative care on a global scale.

The field of palliative care is at a unique crossroad with multiple new global initiatives and new stakeholders calling for palliative care as a component of universal health coverage. The 2014 World Health Assembly Resolution 67.19 entitled '*Strengthening of Palliative Care as a Component of Comprehensive Care throughout the Life Course*', offers an extraordinary opportunity for building bridges, with an expansive range of collaborators to

implement what the resolution calls for: '*the strengthening of health systems to integrate evidenced based, cost-effective and equitable palliative care services in a continuum of care across all levels with emphasis on primary care, community and home-based care and universal coverage*'. An ad hoc WHO Advisory Group led by Dr. Xavier Gomez Batiste and the Barcelona WHO Collaborating Centre are advising the WHO Secretariat on the resolutions' plan of action, country demonstration projects and a framework for reporting back to member states in 2016 on progress made.

These efforts emphasise the priority of investing in health and focusing on palliative care as an essential part of health care systems. How the palliative care community leads with innovation, shared learning, technical assistance, research and advocacy in these bridge-building experiments with policy experts will define a future that ensures the vision of palliative care for all in need, independent of country, care setting, age, gender or underlying disease.

PL2 – Supporting family carers in palliative care: what are the main challenges?

## Supporting family carers in palliative care: what are the main challenges?

**Grande G.E.**

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Family members and friends (carers) play a crucial role in enabling people to be cared for at home towards the end of life, and to die there if this is their wish. They also undertake vital psychological and practical support and coordination. However, carers normally come to this role unprepared, learn by trial and error, and often suffer negative psychological, physical, social and financial effects from care giving. Interventions to support carers have so far shown limited impact on their well-being, and we need a better evidence-base and understanding of 'what works'. However, to achieve wider impact, assessment of and support for carers needs to be integrated into regular healthcare practice. This poses challenges that have to be addressed at several levels, for instance; carers may not define themselves as 'carers' or

feel their needs are legitimate; support for carers in their own right may require considerable changes in the way practitioners' work; and service procedures and administrative systems may not easily accommodate carer assessment and follow up. Service providers also need to adapt to changes in family structure, an aging population and a multicultural society. Finally, to provide effective support for carers we must ensure that we truly gain their perspective, and that we address their needs both for supporting the patient (as co-workers) and for preserving their own well-being (as clients). This presentation will provide a broad overview of the wider carer literature, as well as examples from the presenter's work on carer support needs assessment.

## PL3 – Strengthening the role of palliative care at a time of austerity

# Strengthening the role of palliative care at a time of austerity

**Normand C.**<sup>1,2</sup>

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The challenges for palliative care in the context of recent austerity are considerable. More people are living into older age with multiple health conditions and there is increasing awareness of palliative care needs for people with non-cancer diagnoses, so demands are growing. With static or reduced resources there is a tendency to prioritise the urgent (not the important) and where resource allocation is based on cost-effectiveness there is the problem of limited evidence for many palliative interventions. Emerging evidence and understanding offers some pointers to how palliative care can prosper in the time of austerity. This presentation will focus on:

- Circumstances where palliative care can reduce costs as well as improve outcomes and experiences
- Circumstances where palliative care may cost more but be good value for money

- Strategies for building evidence on the cost-effectiveness of palliative care approaches.

It will be argued that we must recognise the diversity of palliative care activities, that we need to move beyond questions such as 'is palliative care cost-effective?', towards understanding the need to evaluate a range of complex interventions, within the ethos of palliative care. Austerity and very limited resources provide a challenge for the development of palliative care, but also an opportunity to question current patterns of health care and the possibility of shifting the focus onto meeting better the complex needs of people with increasingly complex combinations of chronic conditions. It will also be argued that challenges in evaluating palliative care interventions are common to other areas of complex care, and palliative care research can provide wider understanding of issues in measurement and evaluation.



PL4 – Bridging between loss and meaning: when meaning is lost

# Bridging between loss and meaning: when meaning is lost

**Busch C.J.**

*Rigshospitalet, Copenhagen University Hospital, Kirken, Copenhagen, Denmark*

It doesn't make sense, it is meaningless! What is the meaning of this? These statements and questions are frequently heard from palliative patients and their relatives. This often gives health professionals a feeling of insufficiency. A sense of meaning is essential to palliative patients and their relatives but is a relatively ignored aspect as a research topic.

The concept of meaning is a complex and paradoxical concept because meaning is often brought up when meaning is about to slip out of your hands. When palliative patients and their relatives talk about and experience meaninglessness, it is often because they have a clear understanding of what the meaning is,

namely what they have lost or are about to lose. The meaning of life is to many people all the events where it is pointless to ask the question of meaning. And the reaction to the loss of meaning is often anxiety.

The presentation will reflect on meaning, loss of meaning and anxiety as a philosophical, existential and spiritual concept, and demonstrate how palliative patients are talking concretely about meaning and anxiety.

The presentation will identify different levels of meaning, global meaning and situational meaning, and demonstrate a framework for understanding meaning, spirituality and benefit finding in palliative care.

PL5 – State of the science in managing psychological distress

# Dignity, personhood and the culture of medicine

**Chochinov H.M.**

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Few would disagree that acknowledgment of personhood – seeing people in terms of who they are rather than exclusively in terms of whatever ailment they have – ought to be foundational within the culture of medicine. And yet, healthcare is often characterised as impersonal and routinised, with almost exclusive focus on whatever ailment the patient has, and little attention to who the person is. While considerations such as these are often deemed the ‘soft side’ of medicine, their absence has hard-edged consequences, including patient and family

dissatisfaction, individual practitioner and organisation reputational risk, confusion regarding the goals of care; reduced healthcare provider job satisfaction and heightened risk of professional burnout. So how does one go about getting personhood on the healthcare professional radar? What are the obstacles and barriers in doing so, and how can those be surmounted? While these are considerable challenges, the opportunities are worth pursuing and could help transform the culture of healthcare into one of *health-caring*.

PL6 – The role of systemic inflammation in the pathophysiology of symptoms of advanced cancer: state of the science and clinical implications

# The role of systemic Inflammation in the pathophysiology of symptoms of advanced cancer: state of the science and clinical implications

**Fallon M.**

*University of Edinburgh, Edinburgh, United Kingdom*

Cancer related pain, fatigue, depression, anorexia, cachexia and nausea all share a potential biological aetiology, in systemic inflammation. Inflammation is now firmly established as a hallmark of cancer. Inflammation increases the risk of developing certain cancer types (bladder, gastrointestinal, prostate) and anti-inflammatory medications have been shown to delay or prevent certain cancer types.<sup>1</sup>

In the area of prognosis, systemic inflammation has been associated with decreased survival in cancer. In particular, biomarkers of the inflammatory response (C-reactive protein and albumin – combined in the Glasgow Prognostic Score) have been extensively studied and shown to independently predict outcomes in cancer

patients at diagnosis.<sup>2</sup> In advanced cancer, this has also been demonstrated initially in pilot work (n=100) and corroborated by an international biobank analysis (n=2500), and that systemic inflammation independently predicts survival in patients in the last six months of life.<sup>3,4</sup> Symptoms have also been shown to be related to systemic inflammation in both basic science and clinical studies.<sup>5</sup>

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## PL7 – Awarded Presentations

# The Danish Palliative Care Trial (DanPaCT), a randomised trial of early palliative care in cancer: results of the primary analysis

**Groenvold M.<sup>1,2</sup>, Petersen M.A.<sup>1</sup>, Damkier A.<sup>3</sup>, Gluud C.<sup>4</sup>, Higginson I.J.<sup>5</sup>, Lindschou J.<sup>4</sup>, Neergaard M.A.<sup>6</sup>, Pedersen L.<sup>7</sup>, Sjøgren P.<sup>8</sup>, Stromgren A.S.<sup>9</sup>, Vejlgård T.B.<sup>10</sup>, Johnsen A.T.<sup>1</sup>**

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<sup>10</sup>Vejle Hospital, Lillebaelt Hospital, Palliative Team Vejle, Vejle, Denmark

**Background:** Following the landmark randomised trial (RCT) showing quality of life and survival benefit of early SPC in metastatic lung cancer (Temel, NEJM 2010), and the cluster-RCT by Zimmermann (Lancet 2014), the need for additional randomised trials is well recognised.

**Aim:** To determine whether patients with metastatic cancer, who reported palliative needs in a screening, would benefit from early SPC (i.e. referral to a palliative care team).

**Methods:** This multicentre RCT compared early SPC plus standard care vs. standard care (planned N=300). Consecutive metastatic cancer patients at five oncology departments with no prior contact with SPC were screened for palliative needs. Patients with scores exceeding a certain threshold for physical, role or emotional function, or nausea/vomiting, pain, dyspnoea, or lack of appetite in the EORTC QLQ-C30 questionnaire were eligible. The primary outcome was the change in the patients' primary need (the most severe of the seven

QLQ-C30 scales) to three and eight weeks follow-up, measured as area under the curve (AUC). Five sensitivity analyses were conducted. Secondary outcomes were change (AUC) in the seven QLQ-C30 scales and survival.

**Results:** In total, 145 patients were randomised to early SPC and 152 to standard care only. Early SPC had no significant effect on the primary outcome (difference favouring early SPC was -4.9 points (0-100 scale); p=0.14). The five sensitivity analyses showed similar results. The 95% confidence interval (-11 to +1.5 points) does not exclude the possibility of the hypothesised difference of -7.5 points favouring early SPC. Analyses of the seven secondary outcomes also showed no differences, maybe with the exception of nausea/vomiting, where early SPC might have a beneficial effect. We found no effect on survival.

**Conclusion/discussion:** We discuss whether the negative/neutral findings (see above) can be attributed to the selection of patients, outcomes, analytic strategy, the intervention, or to bias.

## PL7.2 – Awarded Presentations

# The Myeloma Patient Outcome Scale (MyPOS) – longitudinal validity and reliability of a measure of quality of life for clinical use in patients with multiple myeloma

**Ramsenthaler C.<sup>1</sup>, Osborne T.R.<sup>1</sup>, de Wolf-Linder S.<sup>1</sup>, Siegert R.J.<sup>2</sup>, Gao W.<sup>1</sup>, Edmonds P.M.<sup>3</sup>, Schey S.A.<sup>4</sup>, Higginson I.J.<sup>1</sup>**

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**Background:** Patients with multiple myeloma, an incurable cancer of the bone marrow, now live five years or longer with their disease. Severely impaired quality of life (HRQOL) has been described in this patient group, yet HRQOL is not yet routinely assessed or monitored in clinical care.

**Aim:** The aim of this study was to validate a myeloma-specific HRQOL questionnaire suitable for use in clinical practice.

**Method:** Patients were recruited from 18 haematological centres in the UK. Development and validation of the MyPOS comprised: a) item generation through 40 qualitative interviews and three focus groups with patients and health care professionals, b) cognitive testing and item reduction, c) cross-sectional psychometric evaluation to check internal consistency, acceptability/interpretability, structural validity (exploratory and confirmatory factor analysis, Rasch analysis to create unidimensional scales), known-group comparisons and correlational analysis, and d)

longitudinal evaluation in the form of test-retest reliability and sensitivity to change.

**Results:** A conceptual model of health-related quality of life in multiple myeloma formed the basis for item development. The initial 33-item version of the questionnaire was reduced to 27 items after cognitive interviews. Validation (n = 506) showed very good internal consistency ( $\alpha = 0.89$ ) and good test-retest reliability. A three-factor structure (Functioning/symptoms, Emotional problems and Health care factors/information) was confirmed. The MyPOS and its subscales showed a strong ability to distinguish between clinically relevant groups, good convergent and discriminant validity to hypothesised subscales of EORTC and EQ-5D, and sensitivity to change.

**Conclusion:** The MyPOS is a reliable and valid instrument that can be used to assess and monitor HRQOL in clinical practice for multiple myeloma patients of all stages.

**Funding:** Myeloma UK, St Christopher's Hospice, National Institute of Health Research.

## PL7.3 – Awarded Presentations

# My contribution to palliative care research

**McLoughlin K.**<sup>1,2</sup>

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My interest in the field of palliative care research dates back to 2002, when I worked on a Palliative Care Needs Assessment in Ireland. The study highlighted the fear and stigma associated with palliative care, and in 2005 I was awarded the HRB/IHF Building Partnerships for a Healthier Society Research Award to further investigate attitudes toward palliative care from a range of perspectives. This study formed the basis of a PhD in psychology that aimed to (1) examine and compare the attitudes of health professionals toward palliative care; (2) examine and compare the attitudes and personal constructs of four key participant groups including patients receiving palliative care services, people living with cancer and their carers and (3) examine potential strategies for changing attitudes through education.

The outcomes associated with the study achieved far more than these original aims. The research provided a deeper understanding of the ethical complexities of research in this area; included the development of a new

tool – The Health Professional Attitude Questionnaire (HPAQ); saw the development of both an e-learning package for health professionals and an intervention for people living with cancer; provided an eight-variable comprehensive framework to describe health professionals' attitudes toward palliative care; examined how rep grid technique could be utilised in palliative care, but most importantly served as the catalyst to the development of Ireland's first health promoting palliative care demonstration model at Milford Care Centre.

Since graduating, I have engaged in a variety of national research studies and in 2014 was awarded the AIIHPC/ICS Postdoctoral Research Fellowship to conduct an exploratory delayed-intervention, randomised, controlled trial to assess the feasibility, acceptability and potential effectiveness of a volunteer-led model of social and practical support for community dwelling adults living with advanced life-limiting illness.

PL8 – Debate: Individual autonomy versus relational autonomy in the context of clinical care in different parts of Europe – what is best for palliative care?

# Individual autonomy versus relational autonomy in the context of clinical care in different parts of Europe – what is best for palliative care?

**Larkin P.J.<sup>1</sup>, Peruselli C.<sup>2</sup>**

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The perception of autonomy is a critical determinant in the delivery of good palliative care practice. Clinical decision-making reflects autonomy as the absolute and individual right of the individual to self-determination (the value of personal autonomy) or, the belief that autonomy is mediated by wider social- and community-orientated values (sometimes termed a relational autonomy).

Personal autonomy validates the right of the patient to be fully informed about treatment so that appropriate choices can be made; an overriding principle upon which other ethical decisions hinge. Its strength lies in the primacy of the patient, avoiding inappropriate interference in decision-making by family carers and clinical paternalism in care management. Given the need to make judicious decisions at a critical time in people's lives, we need to establish this principle in the provision of care, and clinicians have a duty of care to support their patients to achieve this at all costs.

Conversely, there is also a growing argument that personal autonomy fails to appreciate the reality that

most people in society make decisions within community and based on relationship, rather than only for themselves. The key issue is not autonomy but respect, endorsed through adopting a relational ethical stance. This approach contends that decisions can only be made in the context of engagement with those who hold meaning for the patient, challenges the paternalism of healthcare and may advocate for the patient and family to take appropriate actions, which may be contrary to the given system and culture. To this end, relational autonomy may be more meaningful for the practice of palliative care than current expressions of personal autonomy.

In this debate, Dr Carlo Peruselli and Professor Philip Larkin will argue the respective case for personal and relational autonomy with regard to palliative care. Using case exemplars from practice, they will provide a platform to consider how a 'North-South' divide in the place of autonomy and decide which has the most positive outcome for the patient, the discipline and the practice of the healthcare professional.



# Parallel Sessions

- PS01** Debate: Hospices that provide comfort care only, undermine the palliative care commitment to individualised, goal-focused care
- PS02** Controversies around palliative care for people with dementia: building bridges between palliativists and other specialists
- PS03** Assessing and managing breathlessness in palliative care
- PS04** Public health approaches to support evidence based palliative care practice
- PS05** Sleep disorders, anxiety, depression: complex syndromes in advanced cancer patients and how we can manage them better?
- PS06** Implementation of advance care planning
- PS07** Implementing Patient Reported Outcome Measures (PROMs) in clinical practice: guidance and experiences
- PS08** Bridging research and policy: economic evaluation in palliative care
- PS09** Recruiting to palliative care studies in Europe – developing recommendations for best practice
- PS10** Examining trends in place of death: methods, results and meaning
- PS11** User involvement in palliative care – do we need bridges between the knowledge of professionals, patients and relatives?
- PS12** Paediatric palliative care: moving forward
- PS13** Palliative sedation in a European context: epidemiology, practice and guidelines
- PS14** How to develop palliative care in the community throughout Europe
- PS15** How to undertake research on meaning making and existential issues
- PS16** Moving forward in bereavement care: emerging issues in service delivery in Europe
- PS17** EAPC cancer pain management guidelines: update of pharmacological and non-pharmacological treatment recommendations, including guidance to assessment and classification
- PS18** Improving quality of palliative care in long term care facilities in Europe: first results from an EU funded project PACE (FP7)
- PS19** Moving forward spiritual care in Europe: the EAPC Spiritual Care Taskforce
- PS20** Building bridges between countries: reporting research to have international resonance

## PS01

## Debate: Hospices that provide comfort care only, undermine the palliative care commitment to individualised, goal-focused care

Abstract number: PS01.1

Abstract type: Parallel Session

**Hospices that provide comfort care only, undermine the palliative care commitment to individualised, goal-focused care: the argument for***Cherny N.I.*

Shaare Zedek Medical Center, Oncology and Palliative Care, Jerusalem, Israel

This debate was triggered by a case of a 70-year-old man with advanced pancreatic cancer who was referred for inpatient palliative care. He had a resolving cholangitis and was on antibiotics. The family was distraught to hear that the hospice did not provide antibiotics, do blood tests, administer blood or even check vital signs. Incredulous, I called to speak with the physician in the hospice who explained that they aim to ensure patients are comfortable and not suffering, but don't provide life-prolonging therapies (of any sort). In a subsequent discussion on the EAPC Blog it emerged that the model of *demedicalised terminal care only* in which only 'comfort care' is provided is common in German hospices and in sporadic settings elsewhere. This approach is at variance with the EAPC consensus definition of hospice which emphasises the *provision of care based on individual need and personal choice*. This variance harms the image of palliative care: it undermines the professional commitment to individualised, goal-focused care that is at the very heart of our professional enterprise. It negates the preservation of function and duration of survival as legitimate goals of care as patients approach their death, it reinforces the pejorative stereotype that palliative care is only about the care of the dying not about improving the lives of those with life-limiting disease and it projects palliative/hospice care and a medical subspecialty bereft of standards of practice. If for economic or infrastructural reasons one wants to maintain centers for 'demedicalised terminal care' as a subspecialty of service of palliative (hospice) care, these units should be clearly identified as 'centres for terminal care', indicating their limited scope of palliative care services.

Abstract number: PS01.2

Abstract type: Parallel Session

**The Case against: Hospices that Provide Comfort Care only, Undermine the Palliative Care Commitment to Individualized, Goal-focused Care***Radbruch L.*

University Bonn, Department of Palliative Medicine, Bonn, Germany

Modern hospice and palliative care have evolved in contrast to high-tech medicine, focusing on pain and symptom relief, but rejecting all therapies that were aimed at curing the underlying disease. When I came into contact with palliative care twenty years ago in Germany, palliative care units and hospices made it clear that cancer patients would not be admitted unless it was definitely clear that they would not receive any chemotherapy or radiotherapy.

However, there has been a change of paradigm since then. Cancer patients with bone metastases will routinely be presented for radiotherapy. In Germany 13% of cancer patients treated in palliative care units receive chemotherapy. Blood transfusions and tube feeding are always discussed in the team, and if deemed beneficial will be offered to the patient. Potential benefits that are discussed in the team and with patient and family are not only symptom control, but also life prolongation, for example if the patient has a specific reason to want that (such as a family celebration) and there is a realistic chance to achieve this individual goal.

In addition, the expansion of palliative care from cancer patients to other patient groups requires technical support in some cases. Patients with advanced motor neurone disease cannot be admitted unless respiratory support is available.

All in all, modern hospice and palliative care requires not only the knowledge, skills and attitudes for comfort care, but also access to interventions such as transfusions, antineoplastic therapies, tube feeding or respiratory care. This does not mean that these therapies should be used automatically, but rather that individualised care in some selected patients, after careful discussion with patients and significant others, may provide an indication for their use.

## PS02

## Controversies around palliative care for people with dementia: building bridges between palliativists and other specialists

Abstract number: PS02.1

Abstract type: Parallel Session

**The Controversial Issues around Palliative Care in Dementia: observations from the EAPC White Paper Expert Panel***van der Steen J.T.*VU University Medical Center, EMGO Institute for Health and Care Research, General Practice and Elderly Care Medicine, Amsterdam, Netherlands  
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People with dementia may benefit from palliative care, but in practice it may be unclear when 'usual dementia care' ends, or should be complemented by palliative care, and what palliative care in dementia entails exactly. To define palliative care for dementia patients as distinct from palliative care for other patient groups based on evidence and consensus, the EAPC white paper on palliative care in dementia (published in 2014) employed a Delphi study design. It describes the important domains and for each domain it provides recommendations. Experts in palliative

care, dementia care or both from 23 countries agreed on almost all domains and recommendations, but also identified controversial issues which are particularly relevant in dementia.

We will highlight three salient but sensitive issues. Applicability of palliative care through dementia stages, and treatment of food and fluid intake problems reached moderate consensus only, and prognostication was the most heavily revised domain that was perceived the least relevant. Regarding applicability of palliative care in dementia, some experts expressed concerns about bringing up end-of-life issues prematurely and about relabeling dementia care as palliative care. Recent analyses identified these experts as often being younger, less experienced, and more often their expertise in dementia dominated over palliative or other expertise.

A shared understanding of palliative care in dementia may support effective collaboration between dementia care and palliative care specialists. Collaboration should not be limited to the last phase of life also because anticipation is a key issue in palliative care and the dementia disease trajectory cannot be predicted well. Building bridges implies that we recognise sensitive issues and the specific contributions palliativists and dementia care specialists can make to optimise palliative care in dementia.

Abstract number: PS02.2

Abstract type: Parallel Session

**Estimating Prognosis in Dementia: why, when and how?***Sampson E.*

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Timely recognition of dying is essential to provide good end of life care; this may offer a better quality of life and death than continued medical interventions. It has been suggested that estimating prognosis is vital in order to provide the most person-centred care and best information to people with dementia and their families and to plan for future need. However, clinicians and care home staff can find it challenging to estimate prognosis and have much to learn from palliative care specialists in the complexities and subtleties of estimating survival when making clinical decisions.

Analysis of recent studies which aim to identify accurate predictors of mortality in older people with advanced dementia gives inconsistent results. Methodology and prognostic outcomes vary greatly between studies. Factors which are commonly studied include gender, nutrition, nourishment, or the ability to eat, followed by increased risk with dementia severity and multimorbidities. Many studies also support the inclusion of increased functional or cognitive impairment as a prognostic indicators. When clinical and functional outcomes are combined into prognostic indices for people with dementia these have low sensitivity for predicting mortality but higher specificity. Prognostic markers may lack specificity to advanced dementia and may better correlate with general mortality risks for nursing home residents; here frailty is also a key factor to be considered.

Thus both tools and clinical judgment are perceived (perhaps rightly) as being unreliable at times. We will discuss the advantages and disadvantages of using prognostic tools in this population. In addition we highlight other philosophies of care which differ from this 'prognosis based' model, including 'needs based' approaches. Importantly we need to work both within and beyond our multidisciplinary teams and to learn to hold and manage uncertainty-another key skill that can be learned from palliative care.

Abstract number: PS02.3

Abstract type: Parallel Session

**Do we Have the Evidence to Make Decisions about Artificial Hydration and Nutrition in People with Dementia?***Volicer L.*

University of South Florida, School of Aging Studies, Land O'Lakes, FL, United States

Severe dementia is a condition in which patients are not able to eat and drink by themselves. During their feeding two problems can occur:

1. Patients start choking and coughing. Cough does not mean that a patient aspirates but is a protective reflex that prevents aspiration. Some drugs which increase cough reduce occurrence of aspiration pneumonia. But even demonstrated aspiration does not always lead to aspiration pneumonia. Antibiotics may only prolong dying of patients with severe dementia. It is possible to keep the patient comfortable without antibiotics, by antipyretic and analgesic administration. Effectiveness of antibiotics depends on the hydration status of the patient and with good hydration the survival is the same whether antibiotics are used or not.

2. Patients refuse to eat and drink. This refusal can be considered a sign that the patient wants to die. Stopping eating and drinking by people without dementia leads to a comfortable death by dehydration. Dehydration reduces respiratory and gastrointestinal secretions and the risk of respiratory distress, vomiting and diarrhea. Dehydration can also reduce sensation of pain. The only disadvantage is dryness of the mouth which can be treated with a small amount of liquid or artificial saliva spray. If somebody is afraid of survival in severe dementia, he/she may state in advance directives that at some stage of dementia he/she does not want to be fed and given fluids.

Tube feeding is not indicated in either of these two situations. It does not improve healing of pressure ulcers, prevent aspiration pneumonia or prolong life. However, it has a lot of drawbacks: discomfort from restraints of a patient who tries to remove the tube, loss of enjoyment of the taste of food and drinks, loss of contact with caregivers during feeding, and tube complications (obstruction, infection, vomiting). Tube feeding is not compatible with palliative care for patients with severe dementia, which is a terminal disease.

**PS03****Assessing and managing breathlessness in palliative care**

Abstract number: PS03.1

Abstract type: Parallel Session

**Assessment of Breathlessness in Clinical Practice***Simon S.T.*University Hospital Cologne, Center for Palliative Medicine, Cologne, Germany  
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Breathlessness is a burdensome and prevalent symptom in many life limiting diseases.  
**Aim:** The aim of the presentation is an overview of the main measures for the assessment of breathlessness in clinical practice including new developments and guideline recommendations.

**Methods:** Review of the literature and descriptive synthesis of study results and guideline recommendations.

**Results:** The assessment of breathlessness in life limiting diseases should be part of a comprehensive symptom assessment including different dimensions of breathlessness and other symptoms. A rigorous exploration of potential causes is essential. The gold standard of the subjective symptom breathlessness is self-assessment by the patient. However, proxy-assessment by carers or professionals is needed when self-assessment is not possible because of cognitive or physical impairment. Well validated uni/multidimensional measurement tools exist. Continuous and episodic breathlessness (including by exertion) should be differentiated to optimise the management strategy. New developments such as neuroimaging may routinely play a role in the future but not at present.

**Conclusions:** Routine assessment of breathlessness should inform individual tailored management plans to improve symptom control in breathless patients.

Abstract number: PS03.2

Abstract type: Parallel Session

**Non-drug Approaches to the Management of Breathlessness***Maddocks M.*

King's College London, Cicely Saunders Institute, London, United Kingdom

Breathlessness is a common and distressing symptom for patients and their families. It is difficult to manage and clinicians often report concern around a lack of practical and effective interventions that they can offer. Non-drug treatments have an important role in the management of the breathless patient as part of a first-line approach, alongside drug treatments, and when the symptom continues despite optimal drug treatment. Many different non-drug treatments exist, which target how the breathless patient breathes, thinks and functions. These include breathing training, positioning, acupressure, relaxation, mobility aids and physical exercise. This presentation will appraise the latest developments in non-drug treatments to manage breathlessness, with an emphasis on those which can be easily adopted into clinical practice. It will also cover emerging non-drug treatments that, depending on further evidence, may become part of clinical practice in the future.

Abstract number: PS03.3

Abstract type: Parallel Session

**Drug Approaches to the Management of Breathlessness***Johnson M.*The University of Hull, Hull York Medical School, Hull, United Kingdom  
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Dyspnoea is a prominent, distressing symptom in patients with advanced cardiorespiratory disease and associated with poor clinical outcomes. While the underlying cause is a mandatory treatment target, many patients have refractory breathlessness which persists despite optimal treatment of the causal condition, especially as their disease advances towards the end of life when the severity and prevalence of breathlessness increases. There is a growing evidence base for complex non-pharmacological interventions targeted at the breathlessness itself, but clinicians have a limited number of symptomatic pharmacological interventions to choose of which opioids, is the only one to have a substantive evidence base to support its use.

This presentation will summarise the current evidence for drug approaches to the management of refractory breathlessness and reflect on clinical and further research implications. As there is more work in the area of opioids, there will be a focus on this group of drugs, but others will be addressed.

**PS04****Public health approaches to support evidence based palliative care practice**

Abstract number: PS04.1

Abstract type: Parallel Session

**Monitoring the End of Life: Discussing the Use and Linkage of Existing Health Care Databases to Monitor the Quality of End of Life and Palliative Care***Houttekier D.*

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Routinely collected databases offer the opportunity to monitor the quality of end-of-life care.

**Death certificate data**

The international place of death study (IPOD) aims to monitor place of death within and across countries. High proportions of hospital death are considered an indicator of poor end-of-life care.

Death certificate data (2008) were collected in 14 countries: Belgium, Canada, Czech Republic, England, France, Hungary, Italy, Mexico, the Netherlands (NL), New Zealand, Spain, South Korea (KOR), US, and Wales. Datasets were integrated into one international database to ensure uniform coding. In each country, death certificate data was linked to data on health care services in the catchment area of the deceased (hospital beds, nursing home beds, general practitioners) and the urbanisation level of the place of residence of the deceased.

Analyses showed substantial variation in hospital death within and across countries in specific patient populations, eg: in-hospital death of people who died from dementia ranged from 2% in NL to 74% in KOR. Between-country variation in hospital death risk remained substantial after controlling for differences in patient and health care system characteristics, indicating room for improvement in many countries.

**Healthcare claims data**

Healthcare claims data, when linked to disease registries, offer the opportunity to monitor the quality of end-of-life care in specific patient populations. If linkage is not possible, algorithms based on healthcare claims and drug prescriptions can be used to identify disease groups.

The databases of the Belgian Cancer Registry and Belgian healthcare claims will be used to monitor the quality of end-of-life cancer care in all deceased Belgian cancer patients, using validated quality indicators. Databases are complete and reliable because both health insurance and cancer registry is legally mandatory in Belgium.

Abstract number: PS04.2

Abstract type: Parallel Session

**Measuring Quality in Palliative Care: Nationwide or Regional Implementation of Quality Indicators for Palliative Care. Feasibility and Potentials for Palliative Care Developments***Currow D.C.*

Flinders University, Palliative and Supportive Services, Adelaide, Australia

Patient reported point-of-care data collection is a fundamental building block of quality hospice/palliative care services. A number of initiatives are happening across the globe that have already demonstrated benefits from the patients' point of view as well as from improved systems performance.

The infrastructure for such initiatives can be modest and the ability to generate meaningful data need not be complex or expensive.

Examples include a number of tools with the common theme being patient reported symptoms and performance status. These can be linked with other important issues such as place of care, transitions of care and place of care at the time of death.

Examples of the initiatives include the Carolinas Program, Cancer Care Ontario, California and the Palliative Care Outcomes Collaborative (PCOC) in Australia. All of these programs are designed to minimise the impact on clinicians' time and maximise the quality and level of data that can be collected against performance of the palliative care services.

Without such measures, it is difficult to gauge the performance of services. With these data, systematic service improvement can be achievable, even in small, poorly resourced services.

Abstract number: PS04.3

Abstract type: Parallel Session

**Improving the Community Approach in Palliative Care: from Healthy Cities to Compassionate Cities. Inspired by the Public Health Policy Approach on "Health for All" by the WHO, what Can Palliative Care Learn from it?***Kellehear A.*

University of Bradford, Faculty of Health Studies, Bradford, United Kingdom

Much palliative care understanding about 'community approaches' to palliative care consists of simple understandings of community-based service provision and clinical ideas of 'patients and families'. These ideas seldom embrace traditional public health ideas of community engagement, community development, and citizenship for health. However, despite these difficulties and challenges, the public health approach to palliative care is growing worldwide. This session will examine concepts of community as part of a public health approach to palliative care. The key reasons behind their important application in palliative care will be described as well as how these ideas underpin and create prevention, harm-reduction and early intervention strategies to address the social epidemiology of death, dying, bereavement and long-term caregiving. Current examples of these concepts and practices from the UK palliative care sector will be provided as well as a guide to the important literature and organisations representing this approach.

## PS05

Sleep disorders, anxiety, depression: complex syndromes in advanced cancer patients and how we can manage them better?

**Abstract number:** PS05.1

**Abstract type:** Parallel Session

### Advances in the Understanding of Assessment and Management of Sleep Disturbances in Advanced Cancer Patients

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**Objectives of the presentation:** To provide a brief update on sleep disorders among advanced cancer patients. This includes discussion of the available data regarding their diagnosis, treatment and follow-up, highlighting the unique aspects pertaining to advance cancer patients.

**Background:** Advanced cancer patients often experience one or multiple psychological symptoms (eg, sleep disorders, anxiety and depression) and physical symptoms (eg, pain, loss of appetite, fatigue, sleep disturbances). These symptoms are a result of co-morbidities, a severe illness affecting multiple systems (eg, immune, neurotransmitter, hormonal and circadian rhythm dysregulation), and powerful treatment with potential severe side effects. Sleep disturbance is frequent and usually underdiagnosed despite its significant impact on quality of life. At the conclusion of this presentation the participants will be able to understand the complexity involved in the diagnosis and the complex interventions needed to successfully alleviate this distressing symptom. In most cases a routine comprehensive assessment and an interdisciplinary approach to patient care and structured management plan should be adapted to the available resources.

**Abstract number:** PS05.2

**Abstract type:** Parallel Session

### Depression and Demoralization: Common Points and Differences

Grassi L.

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Demoralisation, as a continuum state from discouragement to despair, characterised by the patient's consciousness of having failed to meet his or her own expectations (or those of others) or being unable to cope with pressing problems and by feelings of helplessness, or hopelessness, or giving up, is an important dimension to evaluate in medical settings for its prevalence. In fact, demoralisation has been frequently described in the course of medical illnesses, including cancer, as a clinical condition affecting about one-third of the patients. The phenomenology of demoralisation has been shown to have some points in common with depression (eg, sadness, suicide ideation) but other points that seem to differentiate it from depression (eg, sense of subjective incompetence). A number of studies have examined the role of demoralisation in influencing quality of life and the relationship with depression. Several instruments have also been recently developed (eg, Diagnostic Criteria of Psychosomatic Research – Demoralisation module; Demoralisation scale, Subjective Incompetence Scale), with validity studies showing the potentials of these instruments in addressing the differences between demoralisation and depression. Because of the implications of demoralisation in terms of quality of life and dignity experience – irrespective of the fact that demoralisation has been described as a disorder, a syndrome or a clinical condition deserving medical attention – its assessment and treatment are necessary steps and the application of specific tools for demoralisation in oncology is an urgent need.

**Abstract number:** PS05.3

**Abstract type:** Parallel Session

### Insights into Effective Communication: Addressing Distress in the Cancer Setting

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Patients facing life-threatening and life-limiting cancer almost invariably experience psychological distress. Responding effectively to such distress requires therapeutic sensitivity and skill. Our research group examined therapeutic effectiveness within the setting of cancer-related distress, with the objective of understanding its constituent parts. Seventy-eight experienced psychosocial oncology clinicians from 24 health care centers across Canada participated in three focus groups each. A total of 29 focus groups were held over two years, during which clinicians were asked to articulate therapeutic factors deemed most helpful in mitigating patient psychosocial distress. The content of each focus group was summarised into major themes, resulting in an empirical model of therapeutic effectiveness. This presentation will provide an overview of the Empirical Model of Optimal Therapeutic Effectiveness (EMOTE). This model consists of three primary, interrelated therapeutic domains, including

- 1) personal growth and self-care,
- 2) therapeutic approaches, and
- 3) creation of a safe space.

Areas of domain overlap were identified, including therapeutic humility, therapeutic pacing and therapeutic presence. Understanding EMOTE and how it can be applied should improve clinicians' communication skills and the psychosocial care they offer patients experiencing cancer-related distress.

## PS06

Implementation of advance care planning

**Abstract number:** PS06.1

**Abstract type:** Parallel Session

### Implementation of Advance Care Planning in Daily Practice

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Understanding an adult patient's values, goals and preferences for medical treatment is one way to clarify treatment decisions. This is especially true as the patient gets sicker, becomes unable to make his or her own decisions and medical treatments start to have a limited benefit. Efforts to understand these preferences, by relying solely on advance directives documents, have not achieved this goal. The only documented successful approach has been to implement an advance care planning (ACP) system as part of the larger health care system.

An ACP system involves organised interactions between health professionals and patients which ensures that five, successive activities are undertaken. These activities are: 1) ACP conversations are routinely initiated with all patients at some planned point in the care pathway; 2) if patients are willing, they will receive skilled assistance so that they are able to reflect on, understand, and discuss a plan of future care; 3) the plan created will be clear to both the patient and their family, and to any health professional; 4) the plan will be stored in a way that it is available to health professionals in the future; and 5) when it is needed, the plan will be used thoughtfully and respectfully by the treating clinicians.

To create an ACP system that can achieve all five of these outcomes, specific design elements must be considered. Firstly, there must be system design. These include medical record systems, documentation systems, as well as work flows and responsibilities. Secondly, there must be a design of how ACP planning conversations will be conducted and certain health professionals must be trained to facilitate these conversations. Thirdly, there must be engagement materials and decision-aids to support good planning. Finally, there must be continuous, quality improvement to ensure that the other three elements are effective. When these four elements are successfully implemented it can lead to effective ACP and improved care.

**Abstract number:** PS06.2

**Abstract type:** Parallel Session

### Competence in Discussing Advance Care Planning

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While it is recognised that it is time to move from the mere completion of an advance directive (AD) document to a broader process of communication, it is unclear what competencies those who facilitate ACP should have and which type of training interventions are most beneficial.

The competence represents a cluster of related abilities, commitments, knowledge and skills that enable a person to act effectively in a certain role and situation. There are rare ACP models with standardised education program which entails an agreed content of ACP and therefore a clear set of competencies. In one of the most researched ACP models, the Respecting Choices (RC), the basic needed competencies to guide ACP facilitation are stated in the definition: a person-centred, ongoing process of communication that facilitates individuals' understanding, reflection, and discussion of their goals, values, and preferences for their future health care decisions and to help loved ones be better prepared. The ACP interview themes proposed as a base framework for a competency development for facilitators are: individual's experiences with illness, fears, religious or cultural beliefs and goals for living well, among others. Such themes can serve as a framework for patients to be able to make informed health care decisions.

At later stages of an illness patients may need more specific guidance in making informed health care decisions, and facilitators need more specific competencies. Person-centred interview skills to encourage moving from 'precontemplation' to action (from no interest in taking action to participating and making changes) are a promising missing link for a successful set of facilitators' competencies in ACP process.

**Abstract number:** PS06.3

**Abstract type:** Parallel Session

### Translation of the Intervention and Adapting it to Different Contexts

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**Aims:** To translate and adapt the US-developed advance care planning (ACP) intervention 'Respecting choices' to a different context (Europe instead of US; advanced colorectal/lung cancer patients instead of the general population) for use within the EU FP7-funded ACTION Project.

**Methods:** The first phase consisted of translation of the core document for recording of the patients wishes ('My Preferences'), the two interview guides, and additional materials. These materials were evaluated in the consortium and in interviews with experienced health care professionals (HCPs). The second phase was a testing of the revised intervention in 4–5 advanced cancer patients in each of the countries (Belgium, Denmark, Italy, Netherlands, Slovenia, UK). After the interviews, patients were interviewed about their experience and the facilitators made detailed notes. In parallel, HCPs were interviewed about the core documents.

**Results:** The first phase led to several revisions in the My Preferences Form and interview guide, most importantly omission of some treatment options, which were deemed irrelevant in the new target population. New questions exploring the patients'



understanding of their disease and treatment were added.

The second phase in ongoing. Initial findings are large differences in the use of ACP prior to the study in the six countries, ranging from Belgium already having an ACP form in place to Denmark and Slovenia, where ACP was largely unknown by patients and HCP. Whereas in Belgium it was important to explain the relationship between the existing ACP form and the new intervention, more basic information about ACP was needed in countries unfamiliar with ACP. A newly developed question about 'Goals for future care' evoked the many comments and may need revision.

**Conclusion:** The detailed feasibility testing was clearly relevant, and important changes to the original documents and interview guides are made, hopefully optimising the intervention before large scale testing.

## PS07

### Implementing Patient Reported Outcome Measures (PROMs) in clinical practice: guidance and experiences

**Abstract number:** PS07.1

**Abstract type:** Parallel Session

#### Implementing Patient Reported Outcome Measures (PROMs) in Clinical Practice: Guidance and Experiences

*Bausewein C.<sup>1</sup>, van Vliet L.<sup>2</sup>, Murtagh F.E.M.<sup>2</sup>*

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PROMs are increasingly being used in research, but less so in clinical practice. This might be because there seems to be a lack of guidance on how to do implement and use them in clinical care. In this parallel session, organised with strong inputs from the Taskforce on Patient Reported Outcome Measures, we aim to help build the bridge between using PROMs for research, to simultaneously using PROMs for clinical care and research (including clinical care only).

We will first discuss the added value of outcome measurement in clinical palliative care. This is followed by the presentation of developed guidance on how to use PROMs in clinical care, using an 8-step framework and including concrete recommendations. Next, a detailed example of a project using and implementing PROMs in clinical care (and research) will be presented. Lastly, a discussion will be held including the public in which ideas and experiences on implementing PROMs in clinical practice are discussed, and which can move the field forward.

**Speakers** (3 presentations, with each presenter being the first author on one of them):

1. Prof Dr Claudia Bausewein – Munich University Hospital, Department of Palliative Medicine, Munich, Germany – Outcome measurement in palliative care – do we really need it? (Munich University Palliative Care Department)
2. Dr Liesbeth van Vliet – Research Associate at Cicely Saunders Institute, London United Kingdom – Guidance on the use and implementation of PROMs in clinical care
3. Dr Fliss Murtagh – Reader and Consultant in Palliative Care, Cicely Saunders Institute, London United Kingdom – Outcome Assessment and Complexity Collaborative (OACC): A project on implementing routine outcome measurement into practice across settings.

## PS08

### Bridging research and policy: economic evaluation in palliative care

**Abstract number:** PS08.1

**Abstract type:** Parallel Session

#### Economic Evaluation - Not Just Counting Beans

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No longer can governments be expected to treat palliative care as a charity case. Increased financial pressure from the global economic recession and fiscal crisis on already stretched budgets means tough decisions have to be made about where to wisely invest limited funds. Consequently, the value of palliative care's contribution to improving health needs to be clearly demonstrated. Health economics is a vital component of planning and funding future health services and providers increasingly rely on economic evaluations to inform resource allocation decisions. However, such research is largely lacking for palliative care programs, services and interventions and the provision of palliative care globally is hampered by the absence of health economic research.

Palliative care clinicians, researchers and administrators ignore health economics at their peril. Ultimately, patients and families receiving palliative care will be disadvantaged whilst such evidence remains lacking and other disciplines secure the lion's share of health resources. If palliative care is to procure a larger slice of the healthcare pie then justification of how such funds will grow services and provide better outcomes for patients and families using the best available clinical and cost-effective arguments needs to be provided to meet funders and policy-makers' information needs.

This presentation will review the clinical and research imperatives for conducting palliative care economic evaluations, introduce the fundamentals of economic evaluation in palliative care, the advantages of conducting economic analyses, and evaluation design. Practical examples will be drawn from the Australian Palliative Care Clinical Studies Collaborative (PaCCSC) trials such as the within trial cost-effectiveness analysis of the randomised, double-blind, placebo-controlled trial of ketamine.

**Abstract number:** PS08.2

**Abstract type:** Parallel Session

#### Outcome Measurement in Palliative Care Economic Evaluations

*Coast J.*

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**Aims:** Economic evaluation standardly assesses outcome with Quality-Adjusted Life-Years (QALYs) based on generic health instruments. For end-of-life care, this means ignoring important non-health, non-patient outcomes. This presentation explores a new framework for outcome measurement in economic evaluations of end of life care.

**Methods:** An overall framework for economic evaluation has been generated and populated through individual studies within the ERC funded EconEndLife project. Qualitative methods have been used to develop two measures to capture impacts on patients (n=23) and close persons (n=27). Best-worst scaling with the general population (n approx 6000) has been used to generate values for the patient measure; deliberative methods have been used with focus group participants (n=38) to generate preliminary values for the close person measure. The patient measure has been tested for feasibility using 'thinkaloud' interviews with 72 patients, close persons and health professionals. Focus groups are also being used to generate values for combining across the measures.

**Results:** The ICECAP-Supportive Care Measure has been generated for patients. It assesses choice, love and affection, physical suffering, emotional suffering, dignity, support, and preparation. Think-aloud work suggests patients can complete the measure, and values have been obtained; the greatest impacts on end of life seem to arise from support, love and affection, and dignity. The ICECAP-Close Person Measure has been developed for close persons. It assesses communication, practical support, privacy and space, emotional support, preparing and coping, and emotional distress, with highly valued attributes being communication and practical support. Early analysis indicates that the public support a positive weight for close persons when combining the measures.

**Conclusions:** New frameworks for the economic evaluation of end of life care can offer greater richness than the current cost/QALY gained.

**Abstract number:** PS08.3

**Abstract type:** Parallel Session

#### Economic Evaluation of Palliative Care - Challenging, but Feasible

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There are two main reasons why it is now important to develop evidence on cost-effectiveness in palliative care – to compete for resources in the increasingly competitive environment of health care financing, and to make better decisions in how palliative care resources are used. While there are challenges in measuring costs and outcomes in many areas of health care, these can present in more extreme ways in palliative care. Drawing on evidence from the Economic Evaluation of Palliative Care study, IARE and other research, this paper considers the issues in measurement in palliative care, and how these can best be overcome.

It is common, but wrong, for economic evaluation studies to take the perspective of the funders. Often this does not matter since most of the costs fall on the delivery of care. Palliative care research shows that a significant part of the cost falls on families and informal carers, as well as many of the benefits. More importantly, there are difficulties in measuring outcomes and benefits in ways that are comparable with studies in other parts of the health system. This is partly because palliative care is a complex intervention with complex effects on many different parties. It is also because the objectives are not inherently measurable in terms of duration of improved functioning – it is really to create a better (in many senses) trajectory of wellbeing until the end of life (which may be a long period). This is a case where the best may be the enemy of the good. Understanding the dilemmas and using the best available tools and approaches can provide evidence that is useful in allowing better choices around what to provide and how to provide it.

## PS09

### Recruiting to palliative care studies in Europe – developing recommendations for best practice

**Abstract number:** PS09.1

**Abstract type:** Parallel Session

#### Reflections on 10 Years of Recruitment in the Palliative Care Setting

*Farquhar M.<sup>1,2</sup>, Preston N.<sup>3</sup>, Ewing G.<sup>4</sup>*

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Recruitment of patients to research is challenging in any setting, but particularly so in the context of advanced disease with the multiple gatekeepers of well-meaning clinicians and families who may seek to 'protect' patients from study participation by controlling researcher access to them. For example, clinicians may exclude some patients who meet study inclusion but not exclusion criteria, or opt not to support study recruitment out of concern for patient burden. This is despite a growing literature on the preferences of patients with advanced disease and benefits some experience from participating, and the issue of patient autonomy. Additional restrictions are in place in the UK in relation to ethical and research governance approvals due to the UK interpretation of the EU Directive (Europe-wide legislation on data protection). Even within the UK the interpretation of the Directive varies with secondary care settings including clinical trials nurses in their definition of the 'direct care team', whereas community-based research nurses cannot necessarily access patient notes in primary care. The compounding impact of this on the delivery of studies (and costs) has been widely acknowledged, which in itself has ethical implications. This situation has changed little in the ten years since Ewing *et al* 2004 published a UK paper entitled 'Recruiting patients into a primary care based study of palliative care: why is it so difficult?'. This paper will report empirical data on recruitment to UK palliative care studies for patients with advanced malignant and non-malignant disease in both primary and secondary care settings, and the strategies employed to facilitate that recruitment. Further it will present findings from a recent Cochrane review of strategies to improve recruitment of patients to palliative and end of life care studies via health care professionals. Thus it will contribute to the debate on best practice in patient recruitment to palliative and end of life care research.

**Abstract number:** PS09.2

**Abstract type:** Parallel Session

#### Recruitment in Italy

*Costantini M.*

IRCCS Arcispedale S. Maria NuovaS. Maria Nuova, Palliative Care Unit, Reggio Emilia, Italy

The challenge of recruitment to palliative care studies is well documented, and include ethical and logistical issues related to the specificity of the population of interest: people at the end of their lives and their families. Recruitment refers to an active process of selecting individuals, or structures in some type of cluster trials, potentially eligible for a study. This presentation will assess strategies used in a sample of experimental Italian studies to improve recruitment, by analysing the studies and by interviewing the principal investigators. We will review procedures at study design level and procedures implemented during the study to improve the rate of recruitment. During the last three years at least three Italian trials successfully dealt with this challenge: the randomised trial on the use of non-invasive mechanical ventilation in four respiratory intensive care units (1); the randomised cluster trial on the use of LCP that recruited 16 hospitals (2); and the ongoing randomised trial assessing the effectiveness of early palliative care intervention in gastric and pancreatic cancers (3).

1. Nava S *et al*. Palliative use of non-invasive ventilation in end-of-life patients with solid tumours: a randomised feasibility trial. *Lancet Oncol*. 2013 Mar;14(3):219–27
2. Costantini M, *et al*. Liverpool Care Pathway for patients with cancer in hospital: a cluster randomised trial. *Lancet* 2014; **383**: 226–37.
3. Maltoni M. The Role of Early Systematic Best Palliative Care Versus on Request Palliative Care Consultation During Standard Oncologic Treatment for Patients With Advanced Gastric or Pancreatic Cancers: a Randomised, Controlled, Multicenter Trial. Registered with ClinicalTrials.gov, as NCT01996540.

**Abstract number:** PS09.3

**Abstract type:** Parallel Session

#### Patient Recruitment in the Netherlands: What about the Law of Lasagna?

*Hasselaar J.*

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In 2012, ZonMW (The Netherlands organisation for Health Research and Development) published a generic report addressing problems in patient inclusion. The report distinguished three phases in the inclusion process, namely the calculation phase to estimate the number of people needed, the phase in which researchers and health care professionals select potential respondents, and the phase in which respondents are really asked for participation. Important obstacles are that power calculations are not realistic (phase 1), that researchers are too optimistic about a caregiver's time to join the research and make efforts to recruit patients (phase 2), and that research information is hard to understand for patients or unattractive in other ways (phase 3). RCT's, repeated measures, indirect participation, a rigid protocol, inclusion of family members, and unclear prevalence data are expected to increase the risk at recruitment problems. Lasagna, a pharmacist, is said to have formulated a law stating that the incidence of available patients firmly decreases when an RCT starts and increases when it ends. Palliative care concerns physically and emotionally vulnerable patients, experiencing serious and often fast decline. This was noticed as a major limitation for research in a next Dutch publication on patient inclusion in palliative care (ZonMW 2014). Of 13 reviewed studies in

palliative care, all had experienced problems with patient inclusion. Often, caregivers feel burdened to ask patients to participate in research and logistic problems arise when inclusion has to start and run with patients in advanced stages of life-limiting illnesses. Due to a limited time frame, administrative aspects of Good Clinical Practice may be difficult to implement, limiting participation. However, the report also offers a checklist to improve patient inclusion. Would it be possible to reverse Lasagna's law in palliative care?

## PS10

### Examining trends in place of death: methods, results and meaning

**Abstract number:** PS10.1

**Abstract type:** Parallel Session

#### From Studying Inequity to Projecting the Road Ahead: A Historical Overview of Research on Where People Die and Implications for Care

*Gomes B.*

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Debates about the place where people die have happened within and between countries since the beginning of the modern hospice movement. Research grew to help understand variations in place of death, with a view to enable patients to die where they wish with the best possible care. In January 2015, there were 1584 papers indexed in MEDLINE with keywords of place, location, site or home adjacent to death or dying. This talk aims to provide an historical overview of how research on trends in place of death has developed, from an initial focus on studying inequity in cancer to the latest developments on projections in several countries, from 2008 onwards. Data from analysis of trends in different countries will be compared, with a focus on European variations (countries include the UK, Belgium, Germany and Portugal). The extent to which clinical, individual and environmental factors (including policies) might explain the existing trends will be discussed. Implications for patients and families, health professionals, service management and policy will focus on projecting the road ahead, to ensure that future trends in the 'microgeographies of death and dying' are both sustainable and responsive to people's preferences, addressing the social asymmetries that have been previously identified. Funding: Calouste Gulbenkian Foundation.

**Abstract number:** PS10.2

**Abstract type:** Parallel Session

#### Using Routinely Collected Data to Understand and Improve End of Life Care in Dementia

*Sleeman K.E.*

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Routinely collected data, gathered for clinical or administrative purposes, provides an attractive resource for studying end of life care. It is without many of the challenges associated with primary data collection in people who are dying, offers the potential to study large or even whole populations, and is relatively inexpensive. One source of routine data that has been extensively used in palliative and end of life care is mortality data, derived from death certificates. Data will be presented from project GUIDE\_Care, a temporal and geographical analysis of place of death using whole population mortality data from England. Temporal trends in place of death among people with dementia will be presented, and the clinical implications considered. The advantages and limitations of mortality data, including the impact of variation in death certification and classification practices, will be discussed. Looking beyond place of death, the wider potential of routine data to understand and improve palliative and end of life care will be explored using examples from different healthcare systems worldwide. For example, linking national datasets with clinical databases can provide opportunities to answer questions that single datasets cannot, while technological advances in natural language processing enable a far greater depth of understanding than previously possible. For frail and vulnerable populations, such approaches offer unique opportunities. For these approaches to be successful, close collaboration between clinical and academic sectors is essential.

**Abstract number:** PS10.3

**Abstract type:** Parallel Session

#### Trends in Place of Death in Belgium and Europe, Implications for Public Health

*Houttekier D.*

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**Background:** A high proportion of deaths in acute hospital settings is considered an indicator for poor quality of end-of-life care. Healthcare policies in many countries support out-of-hospital death. We aimed to examine trends in hospital death in Belgium and other European countries.

**Methods:** Data from death certificates of all deaths from chronic life-limiting diseases (1998-2007; Flanders, Brussels Capital Region), and representative samples of all deaths (2007; 2013; Flanders), were used to examine trends in hospital death in Belgium. Death certificate data from all deaths (2003; 2008) in Belgium, the Netherlands and UK were used to examine trends in hospital death in people who died from cancer and dementia related diseases. Data on the availability of beds in hospitals and nursing homes in the proximity of the deceased was linked to death certificate data.

**Results:** In Belgium, hospital death decreased in people who died from chronic life-limiting diseases from 55.1% to 51.7% between 1998 and 2007. In those living in nursing homes, hospital death fell from 31.0% to 21.5%, and was associated with the conversion of

residential beds to skilled nursing beds in nursing homes. Decrease in hospital death was less substantial in those living at home alone (from 68.6% to 68.2%) and those living in a multi-person household (from 63.4% to 61.7%). Between 2007 and 2013 (all deaths) hospital death decreased in nursing home residents (from 21.6% to 17.0%) and people living in multi-person households (from 63.1% to 60.5%), though not in people living alone (increase from 62.0% to 65.8%). In Belgium (-1.1%), the Netherlands (-1.2%), England (-4.3%), Wales (-3.2%) hospital death decreased in people who died from dementia between 2003 and 2008. In patients who died from cancer, decrease was 2.1%, 5.2%, 5.5% and 3.5% respectively. **Discussion:** Trends show a decrease in hospital death in Belgium and across Europe, possibly indicating better quality of end-of-life care.

## PS11

### User involvement in palliative care – do we need bridges between the knowledge of professionals, patients and relatives?

**Abstract number:** PS11.1

**Abstract type:** Parallel Session

#### User Involvement in Palliative Care

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Patient and public involvement (PPI) in research is promoted in UK policy and by research bodies. The benefits of PPI in research are noted with respect to the focus and design of research, and ways in which research is conducted. Involvement within health and social care research is described as 'doing research with, or by, the public, rather than to, about or for the public'. This paper presents three examples of how user involvement has been developed with, or by, the public to support palliative care research. These represent different ways in which user involvement can be undertaken. The examples are:

- (1) the development of an on-going PPI group that has advised on other people's studies;
- (2) an action research study designed and undertaken by an academic researcher and members of the public, researching the development of a local public awareness initiative about end of life; and
- (3) a prospective case study, which involved user-researchers undertaking fieldwork in six care homes for older people; supported by an embedded qualitative evaluation of PPI activity.

The key principles and processes underlying user involvement and their application in these examples are described. Key challenges of user involvement learnt from this work are identified and ways to overcome them presented.

**Abstract number:** PS11.2

**Abstract type:** Parallel Session

#### Sharing Knowledge with Danish Citizens and Patient Organizations

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**Background:** One purpose of the Danish Knowledge Centre for Rehabilitation and Palliative Care is to share knowledge about suffering from life threatening diseases, end-of-life-care, death and dying – not only with professionals, but also with the users of palliative care (PC). We presume, that there is a correlation between shared knowledge and quality of care. Both internationally and in Denmark (DK), there is a need for more knowledge about the wishes and the experiences of the users of the health care system in general, and in PC in particular. For a start

(2012–2014) the centre asked some questions and tried to answer them in a systematic way: **Questions and methods:** What do the Danes already know about severe diseases, death and dying? We did a survey. How can we create a platform of knowledge about PC available for lay-people? We created a 'lay-people-website'. How can we be sure that the knowledge about PC gets to the people most in need of it? We created and evaluated a network-cooperation with patient organisations.

**Results:** The Danes already know which diseases most people die from, and where the most people die. And they want it different for themselves and their beloved ones. The creation of the lay-people website is ongoing, but until now it has not been well visited. Patient organisations did not want to frighten their members with the knowledge about death and dying. After sharing and dealing with this barrier, several of the organisations now share information about palliative care with their members in different ways.

**Discussion:** Sharing knowledge is an important part of user involvement. We identified some challenges, that we would like to discuss with you.

**Abstract number:** PS11.3

**Abstract type:** Parallel Session

#### Common Beliefs and Reality about Hospice and Palliative Care

*Hegedus K.*

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**Background:** In 2011, after 20 year of palliative care experience, I started to collect the common beliefs about hospice and palliative care (PC), since I realised that many misconceptions hinder the PC development.

**Aim:** To learn more about the 'nature' of common beliefs in order to bust them.

**Methods:**

- (1) Comprehensive literature searches with advanced keywords were completed through an online search of PsychINFO, Ovid, MEDLINE, Help the Hospices databases for articles published between 1980 and 2014.

(2) PC specialists from 6 countries were asked to collect the common beliefs in their countries. 'Common' included the beliefs of professionals as well as lay people. Countries were selected from Western, Eastern, Northern and Southern Europe (Denmark, Germany, Hungary, Italy, Serbia and the UK).

**Results:** Based on worldwide literature and own research, most common beliefs are very similar in almost every country, eg, 'there is no difference between palliative care and long-term care', 'palliative care means that medically nothing will be done for you anymore', 'taking morphine: death is approaching', 'palliative care is not far from euthanasia'. Surprisingly, despite the different cultural, religious and political background people have similar beliefs. The difficulty around misperceptions appears to be only partially related to the confusion of commonly used terminology. In fact, people do not want to discuss or know more about PC, since death and dying are still taboos in society, despite our repeated efforts to change attitudes.

**Conclusion:** It seems that people do not want to embrace simple facts and real information related to PC due to the death-dying taboos. Conventional educational methods are not efficient. However, discussing good death and dying is essential.

## PS12

### Paediatric palliative care: moving forward

**Abstract number:** PS12.1

**Abstract type:** Parallel Session

#### Barriers and Facilitators to Responsive Respite in Children's Palliative Care

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**Aims:** Respite is an integral part of children's palliative care and aims to provide a break from the routine of caring for parents. There is a dearth of evidence regarding the frequency, location and type of respite provided although evidence suggests this respite provision varies according to the child's age, diagnosis, geographical location and the family's capacity to meet the child's care needs. This research aims to identify the barriers and facilitators in the provision of respite to children with life-limiting conditions and their families.

**Methods:** Utilising multiple longitudinal qualitative case study design the respite needs and experiences of parents caring for a child with a life-limiting condition were explored. Multiple in-depth interviews were undertaken with parents who were identified by a palliative care team working in a children's hospital. All data gathered were analysed using thematic analysis. Cross-case comparison was undertaken to seek differences and similarities in and between cases.

**Results:** In-depth interviews were conducted with parents caring for a child with a life-limiting condition in Ireland. Nine families (n=33 participants) were recruited and followed for two years. Cross-case comparison revealed that in all cases home was the location of choice for care. Evidence suggests that facilitators to parental use of respite were: honest and open communication whilst maintaining hope; maintenance of child's routine; respect for their child, family and their home; and acknowledgement of parental expertise in caring for their child. Parental choice of carer was also important. Parent's previous clinical experiences in hospital were a major barrier to acceptance of respite.

**Conclusion:** Healthcare professionals need to consider and explore many factors when identifying the barriers and facilitators in the provision of respite care to children with life-limiting conditions.

**Abstract number:** PS12.2

**Abstract type:** Parallel Session

#### The EAPC Core Competencies for Education in Paediatric Palliative Care

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**Background:** Education is an essential component in the development of paediatric palliative care (PPC), thus all health and social care professionals need to be trained to provide high quality PC for children and their families. Thus an EAPC white paper on core competencies for PPC training was developed.

**Method:** A multidisciplinary multinational group of PPC professionals collaborated on the development of the white paper. Information and materials were drawn from existing competency frameworks & curricula to complement documents such as the IMPaCCT standards for PPC in Europe, the EAPC White paper on core competencies and on standards & norms for PC in Europe.

**Results:** Education programmes for PPC should be aimed at:

- a) the acquisition of knowledge,
- b) the development of specific skills,
- c) the capacity of interdisciplinary thinking,
- d) the cultivation of attitudes that promote quality of life,
- e) the ability for self-awareness & reflective practice.

Programmes need to develop practitioners who are 'competent' to provide PPC. Core competencies are identified within the three-tiered approach to education ie:

- (1) The PC approach;
- (2) General PC; &
- (3) Specialist PC.

*Basic education on PC approach* focuses on the general principles & practices of PC, highlighting differences between paediatric & adult PC. *General PPC education* is aimed at



those who come from a paediatric background who need to learn about PC. Minimum competencies are identified under twelve domains. For healthcare professionals requiring *specialist PPC education* the competency framework is broader & encompasses areas such as collaborative practice, leadership, service development, research, education and professional practice.

**Conclusion:** Whilst a growing number of courses & curricula are available on PPC, provision of courses does not meet the need, therefore it is important to extend education opportunities for everyone involved in PPC. It is hoped that this white paper will help people to do this.

**Abstract number:** PS12.3

**Abstract type:** Parallel Session

## Assessing the Population Need for Children's Palliative Care

*Connor S.R.*

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**Aims:** The need for palliative care for children is different than for adults. Children have different diagnoses and trajectories of illness. Too often we try to use mortality data to estimate the number of children needing palliative care, which understates the need. The capacity to deliver Children's Palliative Care (CPC) also varies widely around the world. Accurate data on the need for CPC and the capacity to deliver it is needed to advocate for closing the gap.

**Methods:** The International Children's Palliative Care Network (ICPCN) in partnership with UNICEF recently developed a new methodology for estimating the population need for CPC using prevalence data in addition to mortality. This cross sectional research uses mixed methods to estimate the gap between the need for CPC and the capacity to deliver it.

**Results:** This method was tested in three African countries successfully and is now being expanded to eleven additional countries representing all four World Bank income groups in an effort to do a more accurate estimate of the global need for CPC. Rates per 10,000 child population will be presented.

**Conclusion:** The need for and capacity to deliver CPC has not been accurately measured globally. Preliminary findings from this ongoing research being done by ICPCN in cooperation with UNICEF are presented. More accurate evidence is needed to effectively advocate for CPC globally.

## PS13

### Palliative sedation in a European context: epidemiology, practice and guidelines

**Abstract number:** PS13.1

**Abstract type:** Parallel Session

## Epidemiology of Palliative Sedation in Belgium and the Netherlands

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End-of-life sedation as an option of last resort in imminently dying patients is widely viewed as normal medical practice. However, the practice is the subject of some controversy given its potential for life shortening and misuse, particularly in its most far-reaching form of continuous deep sedation until death, and particularly in Belgium and the Netherlands where euthanasia is legally regulated. While a number of guidelines have laid down the parameters for good sedation practice, it is important to monitor (the evolution of) the practice in terms of its incidence and its decision making and performance characteristics. Depending on the definition used, the incidence of end-of-life sedation varies considerably both in the Netherlands and in Belgium. In both countries, application of the practice has been increasing. A comparative overview of the available estimates is given as well as differences across care settings and patient groups.

Levels of involvement of patients, family and other professional caregivers in the decision are covered, as well as the most frequently quoted (clinical) indications for end-of-life sedation. Performance characteristics of interest relate to the drugs used, the depth and duration of sedation, and artificial administration of nutrition and hydration. Not infrequently a life shortening effect, though limited, is recounted in both countries. Particularly in the Netherlands, research has found that national guidelines led to significant improvements in end-of-life sedation practice.

Though end-of-life sedation is increasingly practiced in the Low Countries, it seems to be performed with increasing diligence and respect of guideline criteria. Mandatory specialist consultation and mandatory documentation have both been proposed as further measures towards improving practice.

**Abstract number:** PS13.2

**Abstract type:** Parallel Session

## Clinical Decision-making in Palliative Sedation Practice in the UK, Belgium and the Netherlands

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**Background:** Extensive debate surrounds the practice of continuous sedation until death to control refractory symptoms in terminal cancer care. We examined reported practice of UK, Belgian and Dutch physicians and nurses.

**Methods:** Qualitative case studies using interviews.

**Setting:** Hospitals, the domestic home, and hospices or palliative care units.

**Participants:** 57 Physicians and 73 nurses involved in the care of 84 cancer patients.

**Results:** UK respondents reported a continuum of practice from the provision of low doses of sedatives to control terminal restlessness to rarely encountered deep sedation. In contrast, Belgian respondents predominantly described the use of deep sedation, emphasising the

importance of responding to the patient's request. Dutch respondents emphasised making an official medical decision informed by the patient's wish and establishing that a refractory symptom was present. Respondents employed rationales that showed different stances towards four key issues: the preservation of consciousness, concerns about the potential hastening of death, whether they perceived continuous sedation until death as an 'alternative' to euthanasia, and whether they sought to follow guidelines or frameworks for practice.

**Conclusion:** This qualitative analysis suggests that there is systematic variation in end-of-life care sedation practice and its conceptualisation in the UK, Belgium and the Netherlands.

**Abstract number:** PS13.3

**Abstract type:** Parallel Session

## Palliative Sedation Guidelines in Europe: Similarities and Differences in Development and Quality of Existing Guidelines

*Rietjens J.*

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Sedation in palliative care has received growing attention in recent years; and so have guidelines, position statements, and related literature that provide recommendations for its practice. Yet little is known collectively about the content, scope and methodological quality of these materials. According to research, there are large variations in palliative sedation practice, depending on the definition and methodology used. However, a standardised approach to comparing and contrasting related documents, across countries, is lacking. This presentation reports on the findings of a study designed to enable thorough and systematic comparison of guidelines on palliative sedation.

## PS14

### How to develop palliative care in the community throughout Europe

**Abstract number:** PS14.1

**Abstract type:** Parallel Session

## Using the EAPC Primary palliative Care toolkit to develop palliative care in the community throughout Europe: an overview

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**Background:** A multi-disciplinary EAPC Taskforce was established in 2012 to help integrate palliative care in primary care across Europe.

**Aim:** To document the barriers and facilitators for palliative care in the community; and to produce a resource toolkit that enthusiasts could use to facilitate the development of primary palliative care in different countries throughout Europe and possibly worldwide.

**Design:**

Step 1) A survey instrument was sent to general practitioners with knowledge of palliative care services in the community in a purposefully diverse sample of European countries. Barriers and facilitating factors relating to providing community palliative care were identified and analysed.

Step 2) A draft toolkit was then constructed suggesting how individual countries might best address these issues and an online survey was then set up for general practitioners and specialists to comment on and develop the toolkit. Iterations of the toolkit were then presented at international palliative care and primary care conferences. An international systematic review of tools used to identify people for palliative care in the community was also conducted.

**Results:** A toolkit has been produced and refined, together with associated guidance, to help primary care and specialist palliative care leaders throughout Europe advocate for and develop palliative care in the community, 'primary palliative care'.

**Conclusions:** The four domains of the WHO Public Health Strategy provided a robust framework to collate the resources and structure the toolkit. The taskforce toolkit usefully supplements previous work to help community based palliative care services to be established to ensure adequate population coverage.

**Abstract number:** PS14.2

**Abstract type:** Parallel Session

## Interprofessional Teamwork within Maisons de Santé Pluriprofessionnelles (MSP) in France. An Opportunity to Develop the Palliative Approach in Primary Care?

*Moine S.*

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**Background:** Access to specialist palliative care services remains limited in France and it does not rely on a community approach. Furthermore, there is no mention of primary care in the National Strategy for the Development of Palliative Care (2008–2012). Multiprofessional Primary Health Care Centers (MPHC) could represent an opportunity to develop the palliative approach in primary care.

**Aim:** To assess the impact of early identification, multidimensional assessment and anticipatory care planning (ACP) by interprofessional teams within MPHCs on the access rates to specialist palliative care services for patients with palliative needs.

**Design:** Based on the recommendations of the EAPC Toolkit, our project targets three dimensions: education, research and advocacy.

1) A simulation-based training is being developed to facilitate interprofessional coordination and ACP conversations in MPHCs.

2) After a feasibility study conducted in a rural MPHC in Picardy, a multicenter mixed-methods study (SCoP3) will evaluate the impact of a complex intervention in MPHCs on the access to specialist palliative care.

3) Several meetings have been held at local and national levels (with health professionals, secondary care services, end of life care volunteers, regional health authorities, representatives of national ethics bodies and a member of the French Parliament), to advocate the development of palliative care in interprofessional primary care.

**Results:** The advocacy part of our project has reinforced the collaboration between our MPHC, a palliative care network (at home) and a palliative care mobile team in our local hospital. Expected results of research should be a better access to palliative care for patients with palliative needs (with a general impact on quality and safety in care).

**Conclusions:** Interprofessional primary care might play a prominent role in access to specialist palliative care. A well-conducted assessment shall nevertheless precede any wider dissemination.

**Abstract number:** PS14.3

**Abstract type:** Parallel Session

### Building Bridges between the Delivery of Primary and Secondary/tertiary Palliative Care - Development of an Integrated Model of Palliative Care Service Delivery in Serbia

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**Background:** In 2009, the MoH in Serbia published a National Strategy for Palliative Care (PC), which acknowledged the need for PC services to be integrated into the government health system and provided throughout Serbia. Therefore a model of PC service delivery was developed to meet the needs of the culture, community and health system, whilst ensuring that it is provided at all levels of care.

**Method:** A process for the development of the model was agreed with the MoH and included: a review of the literature on models of PC delivery, the PC strategy, international and European standards and norms; a field study at primary and secondary levels; and a review of legislation.

**Results:** The model of care was developed by a group of PC and organisational development experts working alongside the MoH. The integrated model of PC service delivery includes the model document,

a resource plan, quality indicators, standards of care, instruments for implementation and best practice guidelines. Thus the model addresses the essential elements of the setting/level of care, a description of services (services provided, types of patients seen, referral processes, linkage), staffing (eg, teamwork, management, co-ordination), institutional resources, access to medications, legislation, tools for implementation (eg, instruments, clinical protocols, standards, quality indicators), training and finance. These have been guided by the principles of access to palliative care for all, training on PC for all, the Government ensuring the policy and legislative frameworks needed, and that PC should be provided through multi-disciplinary teams.

**Conclusion:** An integrated model of PC service delivery has been developed for Serbia. Key components are the delivery of care at the different levels, with clear referral pathways between the primary and secondary / tertiary levels of care. The model has been officially approved by the MoH and work is ongoing for its implementation.

## PS15

### How to undertake research on meaning making and existential issues

**Abstract number:** PS15.1

**Abstract type:** Parallel Session

### Developing and Evaluating Spiritual Care Training for Health Professionals

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**Background:** Many health professionals experience barriers to assessing spiritual needs, such as not having the right vocabulary. The Dutch 'ars moriendi model' might be a feasible tool for spiritual history taking in palliative care.

**Aim:** To investigate the effect of a structured spiritual assessment on the spiritual wellbeing of palliative patients in home care.

**Design:** Cluster randomised controlled trial, conducted between February and October, 2013.

**Patients and methods:** Registered nurses and general practitioners approached eligible patients with an incurable, life-threatening disease for study participation. Health professionals allocated to the intervention arm of the study performed a spiritual assessment based on the ars moriendi model, following a training in spiritual assessment and the use of this model. Health professionals in the control arm provided care as usual. Patient-reported outcomes on spiritual wellbeing, quality of life, pain, and patient-provider trust were assessed at two points in time.

**Results:** Two hundred and forty-five health professionals participated in the study (204 nurses and 41 physicians). Forty-nine patient-provider dyads completed the entire study protocol. The median age of the patients was 75 years (range 41 – 95 years) and 55% of the patients were female. There were no significant differences at any point in time in the scores on spiritual wellbeing, quality of life, pain, or patient-provider trust between the intervention and the control group.

**Conclusions:** This cluster randomised controlled trial showed no demonstrable effect of spiritual history taking on patient scores for spiritual wellbeing, quality of life, health care relationship trust, or pain. Further research is needed to develop instruments that accurately assess the effectiveness of spiritual interventions in palliative care populations.

**Abstract number:** PS15.2

**Abstract type:** Parallel Session

### Assessment, Measurement, and Intervention: Learning from International Development and Validation of an EORTC Measure of Spiritual Wellbeing

*Vivat B.*

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**Background and aim:** In 2002 the EORTC Quality of Life Group began an international project to develop a measure of spiritual wellbeing (SWB) for palliative cancer patients. The final phase, validation field-testing, ran in 2012–2014. The underpinning theory for the study was SWB as subjective and individual, but with three broad domains: relationship with self and others, existential, and religious. This paper considers some of the issues relating to data tools, collection, and analysis which arose for this international collaboration.

**Methods:** In initial study phases, collaborators translated all study documents into their own languages. For field-testing, collaborators translated all documents except the measure, which was professionally translated. Participants completed the provisional measure, then took part in a debriefing interview exploring their opinions regarding the items and asking them for their own definitions of a few items. Study collaborators translated data into English if needed.

**Results:** Collaborators and participants across the whole study were from 18 countries, with final field-testing involving 458 patients in 14 countries on four continents. The tool was found to facilitate discussion with patients, and most patient participants felt that it covered all key issues; this was corroborated by low levels of comments on problems. Cross-cultural issues arose for some concepts, including definitions (palliative care, SWB, ethnicity, and religious activity) and distinctions between terms, eg, higher/greater. Items on God produced some polarised responses, notably in Japan and Iran.

**Conclusions:** Developing tools of this type to be meaningful in multiple languages and contexts takes time and care, and a multi-cultural, multi-lingual focus from the outset. SWB is particular to each individual, and has some cultural distinctions. Thus the content of the measure cannot be exhaustive, but its qualitative traits prompt wider discussion and reflection on related issues.

**Abstract number:** PS15.3

**Abstract type:** Parallel Session

### Obtaining Funding and Developing Research in Existential Issues: An Example of a Programme of Research on Compassion in Canada

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**Aims:** Research investigating spiritual and existential issues has been identified as a research priority by palliative care researchers, clinicians and patients facing the end of life. Despite its putative centrality, obtaining funding, conducting original research, and translating research findings into clinical practice remains a persistent challenge. Compassion is recognised as a marker and medium of spirituality and humanism, by religious traditions and secular philosophers throughout the world. This session will describe the conceptualisation and implementation of an emerging program of research on compassion by a Canadian research team.

**Methods:** After providing a brief background of both the importance and challenges of conducting research within the spiritual/existential domains of palliative care, the rationale for a construct-based research approach will be provided. Two foundational studies, a qualitative study eliciting patients' understandings and experiences of compassion and a scoping review of the compassion literature (in progress) will be utilised as case examples.

**Results:** A program of research on compassion serves as a potential model for conducting other construct based research on spiritual/existential issues by providing a common language that is accessible to patients and clinicians from diverse spiritual and philosophical backgrounds.

**Conclusion:** Compassionate care is a core principle of quality care, especially in palliative care. A construct-based research program on compassion, provides a focused, yet broadly applicable avenue for research and clinical practice into a domain of health that has been characterised as nascent, ephemeral and highly phenomenological.

## PS16

### Moving forward in bereavement care: emerging issues in service delivery in Europe

**Abstract number:** PS16.1

**Abstract type:** Parallel Session

### Identifying Complicated or Prolonged Grief and the Role of Palliative Care Services in Supporting People

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**Background/aim:** Complicated grief (CG) is proposed as a bereavement-related diagnosis for the ICD-11 and treatments have become increasingly effective. A framework for bereavement care based on evidence and equitable resource allocation seems to be supported. Yet, surveys of bereavement services show that bereavement programs struggle with best-practice models. The aim of our studies was to assess prevalence of CG in relatives to deceased palliative care patients and investigate downstream effects of bereavement on healthcare utilisation to scrutinise the need for identification and treatment of CG.

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**Methods:** A nationwide, population-based questionnaire study with the PG-13 scale was conducted to assess CG in a population losing a close relative to life-threatening illness. Furthermore, a nationwide register-based case-control study was conducted to investigate the health care utilisation of persons losing a person to cancer.

**Results:** The first 1043 responses to the PG-13 showed a prevalence of N=64 (6%) according to diagnostic criteria and an additional N=49 (5%) with daily symptoms of bereavement-related distress (mean age=63 years (range 18-91), 69% women). The register-based study included 6,659 bereaved spouses and 66,590 matching controls (mean age=67 (range 23-89), 62% women). Healthcare utilisation showed a distinct increased use of general practice, referrals to psychologists and psychiatrist, as well as psychotropic medication for up to two years after the loss.

**Conclusions:** Using a questionnaire based identification, approximately 11% of bereaved relatives appear to be in need of treatment for CG symptoms. Further, register-based data show important downstream effects indicating serious effects on health and utilisation of services in various parts of the healthcare system. Bereavement care in palliative care settings seems to be in need of discussion of an organisational scope on how to ensure identification and treatment of bereavement-related distress.

**Abstract number:** PS16.2

**Abstract type:** Parallel Session

### Reflections on the Effects of the Crisis in Greece on the Experience and Support of the Bereaved

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Over the past six years, Greece has experienced more extreme austerity than any other European country, in an attempt to decrease its national budget deficit and debt. Greeks were faced, suddenly and within a very short time, with major and multiple losses which have affected their standards and quality of living. Among the most affected populations were those in need of public health and social services that were dramatically decreased. The purpose of this presentation is threefold: (a) to briefly identify some new psychosocial phenomena in a population that is faced with several actual and ambiguous losses, incremental grief, as well as chronic distress over an uncertain reality and future; (b) to discuss how these phenomena seem to affect the grieving process of bereaved families; and (c) to raise awareness on the challenges that professionals encounter when caring for the dying and the bereaved, while facing personal and organisational threats or losses. Reflections will be drawn from my experience at 'Merimna', a not-for-profit organisation for the care of children and families facing illness and death, which provides paediatric palliative home care services in Athens and family bereavement support across the country. Recommendations will address issues on how those of us who work in palliative and bereavement care can expand our thinking, our services, and collaborations in order to address the emerging needs of populations which encounter major hardships.

**Abstract number:** PS16.3

**Abstract type:** Parallel Session

### Frameworks for Service Delivery

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Palliative care bereavement services developed in response to a largely unexpected demand from bereaved people for continuing support. Drawing on counselling models to prevent, or alleviate 'complicated grief', pioneering services typically involved volunteers as the main providers of care in recognition that grief following a close bereavement is a 'normal' part of life. In the UK a national framework developed recognising a need for information about grief for all, and a varying need for supportive or therapeutic counselling. In recent years attention has focused both on recognising and responding to more complex expressions of grief and on increasing awareness and understanding of bereavement in the general public with the aim of developing more compassionate communities. This presentation will discuss the changing role of palliative care bereavement services in the context of: developments in our knowledge and understanding of bereavement and of grief trajectories societal change economic pressures. It will draw on experiences within the UK to help bereavement services to work together to provide a wide range of support across different settings to meet the diverse needs of bereaved people.

## PS17

EAPC cancer pain management guidelines: update of pharmacological and non-pharmacological treatment recommendations, including guidance to assessment and classification

**Abstract number:** PS17.1

**Abstract type:** Parallel Session

### Assessment and Classification of Cancer Pain According to the EAPC Cancer Pain Updated Guidelines

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Lack of standard diagnostic procedures is one important reason for inadequate cancer pain (CP). This underlines a need for standardisation of assessment and classification of CP.

Two systematic literature reviews on CP assessment covering 1966–2003 and 2003–2008, respectively, and one on CP classification systems covering 1986–2006 have been conducted. A total of 91 pain assessment tools were identified used. Six formal classification systems for CP were identified, however none of these were extensively applied in clinical practice or in research. For the basic assessment and classification of CP the following domains are at present recommended: pain intensity (by a 0–10 numerical rating scale), breakthrough pain, neuropathic pain, localisation of pain (by a body map), and psychological distress. Further domains to consider are age, cancer disease, analgesic treatment and sleep disturbances. Genetic factors have not yet been found to have statistically significant influence on opioid response. Existing evidence and an international Delphi process resulted in consensus on 31 core variables for describing a cancer palliative care population including symptom assessment; the EAPC Basic Dataset.

The EAPC Opioid Guidelines from 2012 did not include recommendations regarding assessment and classification. In the revised version of 2015 this topic will be covered. A new systematic literature review on CP assessment and classification is ongoing; results will be presented. Existing evidence and expert opinions will form the basis for recommendations on the most appropriate and the optimal number of domains to include, how they should be assessed, and the appropriate outcomes.

A comprehensive formalised system for CP assessment and classification applying international guidelines is expected to improve CP treatment in the future. A computer based communication tool and decision support system, Eir, will be important in its implementation into clinical practice.

**Abstract number:** PS17.2

**Abstract type:** Parallel Session

### Latest Developments in the Evidence-based EAPC Cancer Pain Management Guideline on Pharmacological Therapies

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In this session I will update the development of the revised version of the EAPC cancer pain management guidelines, based on their previous version published in Lancet Oncology 2012, followed by the work done by the EAPC research network working Group on pain guidelines in the last three years. The EAPC guidelines are evidence-based and follow the GRADE system. After the last release of the EAPC opioid recommendations it was decided to broaden the scope of the guidelines to include cancer pain management in all aspects, from assessment and classification to invasive analgesic techniques. The area of pharmacological therapies was made more comprehensive, including the use of non steroidal anti-inflammatory agents, steroids, ketamine, tapentadol, bisphosphonates and denosumab. All other previously presented topics were updated to 2014 by systematic literature reviews and the related revised recommendations will be presented in order to provide, together with the other speeches included in this EAPC cancer pain guidelines session, the whole content and the status of development of the next release.

**Abstract number:** PS17.3

**Abstract type:** Parallel Session

### Latest Developments in Invasive Analgesic Therapy Recommendations for Cancer Pain According to the Updated EAPC Guidelines and Future Perspectives

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The presentation will be based on three systematic reviews:

- 1) analgesic efficacy and side effects of opioids +/- adjuvant analgesics delivered by spinal route in patients with cancer;
- 2) analgesic efficacy of sympathetic blocks in adult patients with cancer;
- 3) analgesic efficacy of peripheral nerve blocks in adult patients with cancer

**Methods:** Search strategies were built with relevant terms and the search was performed in PubMed, EMBASE, and Cochrane to Feb 2014. All selected studies were analysed according to the GRADE recommendations.

#### Results:

Ad 1) The number of abstracts retrieved for full reading was 84. The final selection comprised nine randomised controlled trials (RCTs): spinal combinations of opioids and adjuvant analgesics compared with spinal administration of opioids alone (n=4); single spinal drug in bolus compared with continuous administration (n=2); single spinal drug compared with spinal placebo (n=1); and spinal opioids combined with or without adjuvant analgesics compared with comprehensive medical management (n=2).

Ad 2) Regarding celiac plexus block (CPB) 155 papers were retrieved out of which 27 controlled studies were considered for evidence examination. Fourteen articles about different approaches for CPB were selected, but only one controlled study of superior hypogastric plexus block (SHPB) was found.

Ad 3) The number of abstracts retrieved was 155. No controlled studies were identified. Sixteen papers presented a total of 79 cases. The blocks applied were paravertebral blocks (10 cases), blocks in the head region (2 cases), plexus blocks (13 cases), intercostal blocks (43 cases) and others (11 cases).

#### Conclusions:

- Ad 1) Heterogeneous characteristics and several methodological limitations resulted in evidence of low quality and a weak recommendation for spinal administration.
- Ad 2) CPB could be weakly recommended in patients with pancreatic cancer pain.
- Ad 3) Peripheral blocks is based upon anecdotal evidence.



## PS18

## Improving quality of palliative care in long term care facilities in Europe: first results from an EU funded project PACE (FP7)

Abstract number: PS18.1

Abstract type: Parallel Session

## Challenges in Comparing Quality of Palliative Care in Long Term Care Facilities (LTCFs) in Different EU Countries

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PACE (EU FP7 2014–2019) performs comparative effectiveness research concerning palliative care in LTCFs (nursing/care homes) in six EU countries (BE, UK, IT, FI, PL, NL) [www.eupace.eu](http://www.eupace.eu). One of its aims is to investigate country differences in quality of care, quality of dying, staff knowledge/attitudes towards palliative care, and costs of care in the last month of life. Via this comparison, we will identify good palliative care practices for LTCFs in terms of optimal care structures, processes and outcomes.

We conducted a cross-sectional study of deaths of residents using proportional stratified sampling. In each country, all participating facilities retrospectively report all deaths of residents in and outside the facilities over a past three month period. For each case, structured after death questionnaires including validated instruments are sent to:

- 1) the administrator/director
- 2) staff member most involved in care
- 3) treating GP
- 4) relative.

Additionally, all staff members of the facility are asked to fill in a knowledge/attitudes questionnaire.

Primary outcomes are staff knowledge/attitudes concerning palliative care, and quality of dying of residents. Secondary outcomes concern quality of palliative/end-of-life care and health care resource use in the last month of life.

During this session we will report on the

- full study design and methods used
- challenges encountered in setting up the study, eg, the complexity of identifying the correct sampling strategy to obtain a representative sample of facilities in each country, differences in ethical procedures per country, problems with translations of questionnaires (cross-cultural and language)
- conceptual model used to analyse the differences between countries in outcomes
- preliminary findings of the study. In each country, we estimate to identify 200 deceased residents. Data collection takes place between March and July 2015 in each country.

Abstract number: PS18.2

Abstract type: Parallel Session

## Palliative Care Accessibility in Long Term Care Facilities (LTCFs) in Six EU Countries (BE, UK, IT, FI, PL, NL)

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An EAPC Taskforce 'Mapping palliative care systems in long term care facilities in Europe' was established within the PACE project to map and classify different structures, organisational models, and policies related to palliative care (PC) provision in long term care facilities (LTCFs) in Europe. A survey of country informants about the structures of LTCFs and PC provision was undertaken, supported by documentary analysis in 29 European countries in total. During this presentation, an overview is provided concerning the results of the EAPC Taskforce, with a specific focus on the differences between the six PACE countries.

Countries have been categorised with respect to the development of PC in the EAPC Atlas of Palliative Care in Europe. Advanced integration of PC is seen in Belgium, Italy, Poland and the UK. Finland and the Netherlands demonstrate preliminary integration. However, it is not clear how this PC development supports residents living in LTCFs and if care for residents dying in LTCFs is appropriate and sufficient. There are both similarities and differences in the structure of LTCFs across these six European countries with respect to regulation, funding, human resources, levels of staff, professionalism and competencies.

Key drivers for the development of PC in LTCFs exist at national, regional and organisational levels, within legal, regulatory and professional frameworks. Challenges with PC implementation into LTCFs concern LTCF structure and organisation, staff competencies in care for dying residents. Diversity in systems and levels of PC education across countries do not assure that LTCF staff are all prepared to provide appropriate care for residents being close to death.

The main conclusion is that accessibility of PC in LTCFs differs between six PACE countries in terms of infrastructure, human resources, organisation and legal regulations. Thus ensuring an appropriate care for residents dying in nursing homes remains an important challenge.

Abstract number: PS18.3

Abstract type: Parallel Session

## An Innovative Intervention to Improve Palliative Care in Long Term Care Facilities in Europe: A Cross-cultural Adaptation

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The PACE Steps to Success intervention is based upon previous work undertaken in the United Kingdom where an intervention, 'The Route to Success' programme, was promoted nationally (building upon the work of the UK Gold Standards Framework (GSF) for care homes) to improve the quality of palliative care in LTCFs. The steps of the intervention address: discussions as the end of life approaches; assessment and review; co-ordination of care; delivery of high quality care: symptom management; care in the last days of life; and care after death.

The intervention aims to integrate palliative care in day-to-day routines to ensure behavioural sustainability. The process of implementation is supported by key personnel: a LTCF coordinator and a country trainer. At the core of the intervention is the nomination of a LTCF coordinator, ensuring each facility has a champion who has access to current national and local information. He/she is supported to develop their knowledge and skills and encouraged to empower staff within their organisation to deliver palliative care. All staff in the LTCFs are supported by the Country Trainer who delivers workshops and provides support and education to all staff.

The intervention implementation process has entailed an iterative process of consultation between the researchers and clinicians in the six countries, and an implementation process review prior to use in the main trial. This session will present the process of adaptation of the intervention to make it suitable for a cross-country study. A Theory of Change has been identified that underpins the intervention and its implementation, and this will be described in the session outlining: the key components of the intervention, the casual pathway and evaluation indicators required for the trial.

## PS19

## Moving forward spiritual care in Europe: the EAPC Spiritual Care Taskforce

Abstract number: PS19.1

Abstract type: Parallel Session

## Building Bridges for Providing Better Education in Spiritual Care

*Paal P.*

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Since the 1980s, when publications focusing on the meaning, definition and assessment of spirituality began to emerge in health related literature there has been a significant rise in spiritual care training provided to health care professionals. Recent studies have pointed out that despite some 'uncertainty and fear surrounding the boundaries between personal belief and professional practice'<sup>1</sup> healthcare professionals have genuine interest in providing spiritual care and building a relationship with their patients. Nevertheless, it remains a burning topic; how, when, to whom, and to what extent spiritual care training should be provided.

This presentation aims to appraise the evidence on aims and outcomes of spiritual care training in order to support the spiritual care curriculum development in an academic and clinical setting. It contrasts and combines the results from different studies in order to identify common challenges and advantages.

Providing training in spiritual care to healthcare professionals is one way to integrate the aspect of spirituality in comprehensive patient care. Considering the need for a change in culture and development of an empirical basis for spiritual care, the Education Subgroup has proposed a list of recommendations<sup>2</sup> for providing better education in spiritual care.

Accordingly, we encourage all the members of the EAPC to carefully review their provision of spiritual care education and invest time into the delivery of training in classrooms or on online and in on-going support through performance assessment and reflective practice.

McSherry W and Jamieson S, *The qualitative findings from an online survey investigating nurses' perceptions of spirituality and spiritual care*. J Clin Nurs, 2013. 22(21-22): p. 3170-82

Paal P, Leget C, Goodhead A, *EAPC Enquiry on Spiritual Care Education*. European Journal of Palliative Care, 2015. 22(2)

Abstract number: PS19.2

Abstract type: Parallel Session

## Generating an International Evidence Base for Spiritual Care

*Speck PW, Selman L.*

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**Background:** In recent years there has been a growing interest in spiritual care research leading to more papers being published in peer reviewed journals. However, the recent Cochrane review (2012) of spiritual care intervention studies for adult cancer patients showed a paucity of studies which met their quality criteria.

**Current initiatives:** I wish to highlight existing gaps in the evidence in relation to spiritual care in palliative care and review some recent initiatives for enhancing research in this area. The work of the EAPC Spiritual Care Taskforce (from 2010) is of note, together with the work of Christina Puchalski in the USA and Europe to create a global network for spirituality and health. Within the UK the End-of-Life-Care programme has undertaken a review of the

literature to inform care planning and the developments of standards. The review demonstrates gaps in the evidence, but they make some salient recommendations. The EAPC Taskforce has offered a working definition for the term 'spirituality' and also completed a survey (Selman *et al* 2014. *J Pain and Symp Mgt* 48(4) 518–531) which sought to establish research priorities in spiritual care from the perspective of researchers and clinicians.

In addition to this survey an InSpirit International focus group study was developed (lead investigator Lucy Selman) with the aim of exploring experiences of spiritual care preferences of patients and carers, leading to further clarification of research priorities. Some of the findings from this study will be reported.

**A future strategy?** Key to developing an international evidence base will be:

- Agreement on research priorities and focus.
- Clarification of appropriate methodological approaches
- Multi-professional collaboration
- The adoption of a pan-European / global approach in order to further develop a network of key researchers in this field.
- Funding, which may easier to attract if planned studies are multi-professional and international

**Abstract number:** PS19.3

**Abstract type:** Parallel Session

## Spiritual Care Quality: The Measure of It

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**Background:** Spirituality is a dimensions inherent to the person. An individual's health and well-being benefit when it is addressed. Spirituality receives great attention; attempts to define it having resulted in important advances to achieve consensus. Measurable Spiritual Care is fundamental to Palliative Care provision.

**Aim:** To conceptualise Spiritual Care by evaluating whether current definitions are fit for purpose and to assess whether its provision can be measured and by which means. A mixed **methods** study design approach was used: Systematic literature review between 1980 and 2014 focusing on Spiritual Care Quality Measurement; Descriptive analysis of European Implementation Survey; Retrospective Analysis of Spirituality fields in the Protocols of Electronic Palliative Care Medical Records; Analysis of survey undertaken by the 24hour PC Team.

**Results:** We found that offering spiritual care is a top concern for professionals. Spiritual Care represents a variety of matters, from assessment to therapy and planning. Implementation efforts are hindered by culturally sensitive spiritual activity. 32% of patients had needs of such complexity that they needed specialist PC. 34% had data on spiritual sphere recorded (89% expressed through religious faith and belief). Its assessment is documented in 14% of cases.

**Discussion:** Questionnaires focused on spiritual activity, engage the focus of professionals. Spiritual Care demands excellent communication. Providing an objective account of the care provided demands flawless documentation within the extended team. Unresolved tension between the subjective and the objective aspects can be an obstacle.

**Conclusion:** Spirituality is well defined. Spiritual Care is not: internationally agreed definition and scoping are needed. Implementation needs strong cultural background, combined with accredited activities and criteria. Documentation of all Spiritual Care activity guarantees robust outcomes measurements, contribute to improve its provision and quality care.

## PS20

Building bridges between countries: reporting research to have international resonance

**Abstract number:** PS20.1

**Abstract type:** Parallel Session

## The Editors' Perspective

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**Aim:** To present the perspective of a journal editor on ensuring a submitted manuscript has international relevance.

**Content:** This presentation will draw from the presenter's experience of editing the EAPC research journal 'Palliative Medicine', an international research journal. Palliative Medicine has readers from every continent, and in the last 6 years has received submissions from 53 different countries. However, not every submission is written to be suitable for this international audience.

Research findings can have broad international applicability and interest irrespective of the local or national context within which data were collected. It is important that the needs of a wide international readership are considered when reporting research: findings could inform practice, policy and further research in wider contexts and avoid needless duplication of research. This presentation will take an editor's perspective to explore what journals look for and expect in a submitted manuscript to enhance its international relevance. Issues explored will include debates about language, definitions and context, claims and over claims; understanding the context of other readers; and drawing from international policy and research literature. The requirement for a clear message from your research will be

discussed, and how to work with a journal to facilitate international dissemination including the use of social media. Researchers should be enabled to better draw out international learning from their own work.

**Abstract number:** PS20.2

**Abstract type:** Parallel Session

## The Research Perspective: Planning and Conducting Research to Have International Resonance

*Cohen J.*

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This presentation will draw from the researcher experience of planning and conducting palliative care research. Palliative care and hospice care can mean very different things across countries. It might refer to different services, to different professionals, to different educational backgrounds, to different patient groups, etc. In order to make a study and paper suitable for an international audience, a researcher has to know the international literature, but also has to understand similarities and differences between palliative care services and processes between different countries.

However, most palliative care practices share the same values, attitudes, knowledge, skills and competences. In order to set up research with international resonance, one needs to reflect about these 'generic issues' that are addressed in a palliative care study in a particular country. Hence, researchers need to reflect about the potential for generalisation of their results for other countries. But also when conducting international comparative research, the comparability of health services and processes between countries need to be made explicit in the research. In reporting the research, the researchers need to take these issues into account when developing the manuscript.

A number of issues will be highlighted in the presentation: How much (national) context do we have to present in the introduction section of the paper? How much context needs to be made explicit in the method section? How much international relevance of your study needs to be addressed in the discussion section? What is the advantage of conducting international research?

**Planning:** Research in palliative care involves a large amount of resources and time. Hence, making an effort in order to gain international resonance will be a marginal additional effort in the whole research process, but your work will have potentially a substantial higher impact.

**Abstract number:** PS20.3

**Abstract type:** Parallel Session

## Building Bridges between Countries: Reporting Research to Have International Resonance. The Reviewers Perspective

*Cleary J.*

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A journal with international readership and authors will have international reviewers and we all want our papers accepted into higher impact journals, yes even the reviewers. This presentation will use the experience of 'Palliative Medicine', the EAPC's Research Journal to give perspective on what authors can do to assist in the review process. The review process starts with the Editors who in fact make a decision as to whether to send the paper out for external review. So ensure that the journal is a good match for your paper. Examples of both good and poor matches will be presented. Language is critical and discussions on the importance of this, especially in Europe will be given.

Don't assume that the reviewers understand the context of your clinical situation. It is important to describe the context in your country and perhaps even make a comparison to another leading country in which other similar research has been conducted. This can be challenging in the face of a word limit.

Review your own paper or have others who are not overly familiar with the work review it. Posing and answering the weaknesses and challenges within your paper, assists the reviewer. Stating the impact and importance of your paper on the international readership, can assist the reviewer in seeing the importance of your paper.

# Meet the Expert Sessions

- ME01** Family carers: evidence based practice
- ME02** Electronic palliative care coordination and decision support systems
- ME03** Palliative care for people with heart failure
- ME04** Developing the relationship between palliative care and neurology
- ME05** How to implement evidence based medicine (EBM) into clinical practice.  
A clinical and health policy perspective
- ME06** Quality improvement in palliative care with the help of indicators:  
the EU-funded IMPACT project
- ME07** European Palliative Care Academy – Leadership Course
- ME08** Core competencies in palliative care social work: key points from the EAPC White Paper; The roles and tasks of palliative care social workers: their views
- ME09** Global palliative care development and the WHA resolution on strengthening palliative care
- ME10** Improving spiritual care in clinical practice
- ME11** What is known about specialist education for palliative medicine?
- ME12** The science of planning and conducting clinical research in palliative care
- ME13** The use of steroids in cancer patients with advanced metastatic disease
- ME14** Integrated palliative care
- ME15** Palliative care in prisons and correctional facilities
- ME16** The future of hospice and palliative care from a volunteering perspective

## ME01

### Family carers: evidence based practice

**Abstract number:** ME01.1

**Abstract type:** Meet the expert

#### Family Carers: Evidence Based Practice

*Hudson P.L.<sup>1,2</sup>, Grande G.<sup>3</sup>*

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Providing support for family carers is a core element of palliative care provision. However, systematic reviews have highlighted the need for more evidence based interventions to assist family carers.

This expert session will focus on:

- (1) Why more needs to be done to improve family carer support
- (2) Challenges faced by health professionals associated with supporting family carers
- (3) Examples of evidence based family carer.

## ME02

### Electronic palliative care coordination and decision support systems

**Abstract number:** ME02.1

**Abstract type:** Meet the expert

#### EIR – An Electronic Decision Support Tool in Oncology

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The European Palliative Care Research Centre has recently conducted a clinical trial (Combat study) employing computerised clinical decision support tools developed in close collaboration with software engineers. Patients completed an electronic questionnaire on an iPad. This data was wirelessly transferred to the desktop PC employed by the clinician and this system also provided electronic decision support for the clinician. The results of this study will be published during 2014. We have further developed this software tool, called EIR, to the next level. In EIR, patients complete an electronic questionnaire by smart phone, tablets or computers. This data is transferred and visualised on the desktop PC applied by the physician in a more intuitive and user friendly style compared to the initial version of the software tool. Additionally, we have developed more complex decision support tools. The content of the talk will focus on the advantages and pitfalls of computerised clinical decision support based on the EIR software tool.

**Abstract number:** ME02.2

**Abstract type:** Meet the expert

#### Coordinate My Care (CMC): A Pan London Clinical Service

*Riley J.L.*

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CMC is a clinical service created by NHS clinicians, for NHS patients. It offers a digital Personalised Urgent Care Plan to patients living in London and Surrey Downs. CMC was set up to improve the identification and coordination of care for palliative care patients who depend on multidisciplinary teams, across acute, community and the voluntary sectors. It is now offered to all vulnerable patients with complex needs. All patients consent to having a CMC care plan, or they may be consented in best interest if they lack capacity. CMC can be accessed by all the urgent care services 24/7, thus vital information is accessible during the out of hours period that represents two thirds of the week. When a CMC urgent care plan is created the Urgent care services are immediately alerted. These services include 111, the out of Hours GP service covering the patient, the patient's own GP and the Ambulance service. Currently 19,817 patients have CMC urgent care plans CMC records, of whom 7,970 have died. In England 54% of patients die in hospital<sup>[1]</sup>, however, for those with a CMC record the number drops to the lowest nationally at 17% dying in hospital and 79% dying in their preferred place. On average, there is a £2,100 saving per patient with a CMC plan by reducing unnecessary emergency admissions and hospital transfer costs<sup>[2]</sup>. Patients will soon be able to access their care plans on their smart phones. CMC thus improves quality of care and decreases costs.

#### References:

- [1] National End of Life Care Intelligence Network (2008-10)
- [2] Source: Frontier Economic Evaluation Report December 2014

## ME03

### Palliative care for people with heart failure

**Abstract number:** ME03.1

**Abstract type:** Meet the expert

#### Unmet Needs in Patients with Heart Failure at End of Life

*Currow D.C.*

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Heart failure is highly prevalent, particularly in resource rich countries. Throughout the world, heart failure without an identifiable aetiology carries an extremely poor prognosis despite the medications that are available to manage heart failure and the option in some settings of even considering transplantation.

The needs of people with heart failure are not dissimilar to any other group within the community - symptom control is crucial, optimising function including mobility is important and ensuring that the other domains that are valued at the end of life are facilitated by excellent attention to detail.

Likewise, caregivers of people with heart failure have very similar needs to other caregivers for people at the end of life. This suggests that there is a 'final common pathway' leading to death that generates similar issues for patients and their caregivers almost irrespective of the underlying disease process.

Cachexia, fatigue, dyspnoea, pain and sleep disturbance are all prominent symptoms, however much more work needs to be done to understand their impact longitudinally in heart failure.

The next 10 years will bring enormous opportunity to understand in more detail through rigorous research the issues faced by people with heart failure as their life limiting illness.

**Abstract number:** ME03.2

**Abstract type:** Meet the expert

#### Patients with Implanted Electronic and Mechanical Devices Approaching Death

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Cardiovascular implantable electronic devices (CIED) encompass pacemakers, implantable cardioverter defibrillators (ICDs) and cardiac resynchronisation therapy (CRT) devices. Some of them function continuously; others monitor rhythm, and only intervene if the device recognises rhythm disturbances. These devices change the trajectory not only of life, but also death, often in a painful manner. The rate of ICD implantations exceeds 30,000 per month worldwide. Every person with a device will eventually die, the majority having a potentially recognisable terminal phase of life. Modification of the activity of the device may improve the quality of dying. Decision-making regarding modification device activity confronts patients, relatives and health care professionals with many challenges. The possibility of modifying device activity in situations where potential intervention no longer fits possible goals should be discussed in advance, optimally while obtaining consent for device implantation. Currently, less than 1% of patients with ICDs draw up advance directives embracing issues in respect of ICD activity. Most patients with an ICD approach death with a fully active device. About 20% of them experience shock therapies in the last days or even hours of life. The deactivation if not performed electronically, can be done in an emergent manner using a magnet.

Implantable mechanical devices – ventricular assist devices (VADs) or artificial hearts – are becoming an increasingly common alternative to heart transplantation. They however, generate difficult end-of-life dilemmas. The appearance of a lethal pathophysiology defines permissibility of withdrawing device support. Turning off a VAD is emotionally challenging, because it is a life-terminating intervention.

The European Association for Palliative Care and Heart Failure Association have created a Joint Task Force to address palliative issues in adults with advanced heart failure.

## ME04

### Developing the relationship between palliative care and neurology

**Abstract number:** ME04.1

**Abstract type:** Meet the expert

#### Developing the Relationship between Palliative Care and Neurology

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A joint working group of the European Association for Palliative Care and the European Federation of Neurological Societies (now the European Academy of Neurology) has produced a Consensus paper on the available evidence for the palliative care in progressive neurological disease, including ALS, multiple sclerosis, Parkinson's disease, stroke and primary brain tumours.

The seven main areas of recommendation are:

1. Palliative care should be considered early in the disease trajectory.
2. The assessment and care should be provided by a multidisciplinary team approach, with



access to specialist palliative care.

3. Communication should be open with patients and families and advance care planning is recommended. This should be as soon as possible in view of the likelihood of difficulties in communication and the development of cognitive changes in several neurological disorders.
  4. Symptoms – physical and psychosocial – should be managed actively and appropriately.
  5. Care needs should be assessed and carers supported before and after death. Professional carers should receive education, support and supervision to reduce the risks of emotional exhaustion.
  6. There should be repeated and continued discussion about end of life issues and discussion of patients' wishes and aims. The recognition of the deterioration and dying phase will allow appropriate management and intervention.
  7. Palliative care principles should be included with the training and continuing medical education of neurologists and palliative care professionals should understand the issues for neurological patients.
- These recommendations have been developed with the aim of improving knowledge and understanding of palliative care for patients with progressive neurological disease. There is now the opportunity to look at developing the relationship between palliative medicine and neurology to ensure that these principles are extended as widely as possible to support patients and their carers.

## ME05

How to implement evidence based medicine (EBM) into clinical practice. A clinical and health policy perspective

**Abstract number:** ME05.1

**Abstract type:** Meet the expert

### How to Implement Evidence Based Medicine (EBM) into Clinical Practice: A Clinical and Health Policy Perspective

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Evidence-based practice (EBP) is the conscientious and judicious use of current best evidence in conjunction with clinical expertise and patient values to guide health care decisions. Best evidence includes empirical evidence from systematic literature reviews, randomised controlled trials, descriptive and qualitative research. Lower levels of evidence, such as case reports and expert opinion, are also used. More than 20 years have passed since an evidence-based medicine working group announced this "new paradigm" for teaching and practising clinical medicine. They proposed tradition, anecdote, and theoretical reasoning from basic sciences would be replaced by evidence from high quality studies, in combination with clinical expertise and the needs and wishes of patients. However, implementing evidence-based medicine in palliative care practice and policies encounters challenges including: level of available research evidence, judgement of evidence, keeping up to date, how evidence is balanced with clinical expertise and patient values, too much evidence, distortion of the brand and the suitability for those with multi-morbidity and/or approaching the end of life.

This 'meet the expert' session will discuss how approaches in evidence-based medicine compare with the seven common alternatives: eminence based medicine, vehemence-based medicine, eloquence-based medicine, providence-based medicine, diffidence-based medicine, nervousness-based medicine and confidence-based medicine. The session will then go on to debate how 'fit for purpose' evidence-based medicine is for palliative care and the implementation of 'real' evidence-based medicine into practice and policy. Participants are encouraged to bring current challenges for discussion.

## ME06

Quality improvement in palliative care with the help of indicators: the EU-funded IMPACT project

**Abstract number:** ME06.1

**Abstract type:** Meet the expert

### IMPACT: Improving the Organisation of your Palliative Care Setting

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**Background:** In the past decade, several sets of quality indicators (QIs) for palliative care have been developed. Yet, mostly these indicators are meant for one type of setting (e.g. intensive care units), one patient category (patients with cancer), focus on clinical outcome or clinical processes (e.g. pain level), are limited to the terminal phase and are developed in one specific country. Besides, just developing QIs does not change practice. A structured improvement project is needed.

**Methods:** We took account of all above-mentioned considerations in our European IMPACT project, in which professionals in palliative care and researchers collaborated. We performed a literature study, focus group interviews, a modified Rand Delphi procedure, a pilot with improvement projects in 40 settings in five European countries (NL, D, I, No, UK) and a nominal group session.

**Results:** We developed of models for the organisation of palliative care, developed QIs for the organisation of palliative care settings, and strategies to improve the organisation of the setting (primary care, hospice, nursing home or hospital). The QIs were used to select topics and aims for quality improvement projects, and to monitor change, in several types of settings and for several patient categories in five countries, and anticipated further dissemination and implementation of our tools.

**Conclusions:** Theory and practice were combined in this project, as well as cancer and

dementia palliative care. We did not stop after QIs were developed, but also developed strategies to use them for quality improvement. With the results of this project we provide scientifically sound, practice-friendly tools to improve the organisation of settings that deliver palliative care all over Europe.

**Abstract number:** ME06.2

**Abstract type:** Meet the expert

### Using Quality Indicators for Service Improvement: An Example from Five European Countries

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The EU-funded multinational IMPACT study has identified quality indicators to improve the organisation of palliative care, not only of patients with cancer but also for those with dementia. The set of 25 quality indicators has been consented by experts from five European countries and includes, for example, access to specialist palliative care, regular assessment of pain and other symptoms, accessibility of opioids and other analgesics, coordinated delivery of health and social care by a designated contact person, regular multidisciplinary team meetings or provision of bereavement support for family care givers as well as for staff.

The indicator set was tested in a sample of 37 services (nursing homes, hospital services, hospices and primary care services) in the five participating countries. For most, a specialised PC team is accessible (25); only 3 did not have access to expert advice in PC. Even though many services offered bereavement support to patient families and team members, standardised procedures were often lacking. Opioids and other analgesics were available around the clock in most services (29).

The services selected specific indicators for the next step of the quality improvement project, and developed specific strategies to implement these indicators. Evaluation of these strategies demonstrated that the implementation required specific dedicated resources, as well as support from the administrative level of the organisation.

In conclusion, the indicator set was found useful by the participating services. The project instigated lively discussions of organisational improvement needs and on the applicability of quality indicators in the surveyed services.

## ME07

European Palliative Care Academy – Leadership Course

**Abstract number:** ME07.1

**Abstract type:** Meet the expert

### The European Palliative Care Academy: Creating Leaders in Palliative and End of Life Care

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Across Europe, palliative care is an increasingly important public health issue due to population ageing, the increasing number of older people dying from advanced diseases, and insufficient attention to their complex needs, and their families. Developing a highly skilled workforce is critical if we are to best serve this population. The European Palliative Care Academy represents a joint venture to train emerging leaders in palliative care across Europe to advance palliative care, and to address future challenges in this important field. Generously funded by the Robert Bosch Foundation, it comprises four highly acclaimed European academic centres: University Hospital Cologne (Germany), Nicolaus Copernicus University in Torun (Poland), Hospice Casa Sperantei in Brasov (Romania) and King's College London (United Kingdom). In this session we will explain the philosophy and content of this exciting new course, describe the successes of our first cohort of course participants, and address any questions from prospective students.

## ME08

Core competencies in palliative care social work: key points from the EAPC White Paper; The roles and tasks of palliative care social workers: their views

**Abstract number:** ME08.1

**Abstract type:** Meet the expert

### Core Competencies in Palliative Care Social Work: Key Points from the EAPC White Paper; The Roles and Tasks of Palliative Care Social Workers: Their Views

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The EAPC Task Force on Palliative Care Social Work was set up to examine the diverse roles and tasks of palliative care social workers across Europe. This task was conceived as a prelude to developing core curricula for the education of all social workers with a palliative care remit. To that end, members of the Task Force consulted with social workers across the European continent, looked at the development and history of social work as a specialism within palliative care - where this had occurred, and considered the emerging literature on the role, particularly that from North America but also further afield. The resulting paper:

Core competencies for palliative care social in Europe: an EAPC White Paper, was published in two parts in recent months. A White Paper is essentially a discussion document meant to stimulate debate and is not intended as the final word on the subject. In his session, Sean Hughes, one of the co-authors of the paper, will begin by outlining some of the key concepts within the article and highlight some areas for debate and consideration. Karl Bitschnau will follow with a short presentation on more recent developments led by the Task Force, in surveying social worker views on their palliative care tasks and roles. He will summarise key findings from this work and will conclude with an outline of next steps in the process. We anticipate that these two presentations will stimulate much discussion and will therefore allow time in this short session for comment, questions and participation from the audience. This session will be of particular interest to social workers, but in a spirit of collegiality we welcome colleagues from all our partner disciplines to join us in our deliberations.

## ME09

### Global palliative care development and the WHA resolution on strengthening palliative care

**Abstract number:** ME09.1

**Abstract type:** Meet the expert

#### Global Palliative Care Development and the WHA Resolution on Strengthening Palliative Care

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In this expert session participants will hear about the latest developments and plans for the WHO to implement the recent resolution "Strengthening of Palliative Care as a Component of Comprehensive Care Throughout the Life Course." This resolution, passed at the World Health Assembly (WHO's governing body) last May, is a major turning point in the global development of palliative care. Countries agreed to call on themselves to include palliative care in all major health policies, to improve the availability of essential palliative care medications, to bring palliative care education into health care professional training at all levels, to begin to fund palliative care program implementation, to do more research on palliative care and more. WHO itself is called on to provide guidance to countries on palliative care and to develop clinical guidelines as well as many technical assistance documents to help countries to strengthen palliative care. An Ad Hoc Technical Advisory Group has been formed to assist WHO in plans for implementation and a strategic plan has been developed to guide work in the coming years. Learn what other countries are doing, and how you can use this opportunity to spur palliative care development in your own country, how to monitor progress and how to use the *Global Atlas of Palliative Care at the End of Life* to benchmark progress.

## ME10

### Improving spiritual care in clinical practice

**Abstract number:** ME10.1

**Abstract type:** Meet the expert

#### Improving Spiritual Care in Clinical Practice

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In this session, we begin with a short introduction on the state of the art of spiritual care in clinical practice as observed by the spiritual care taskforce of the EAPC. Subsequently, we will present some examples of how to improve spiritual care in clinical practice. Those who are present are invited to share their experiences from different contexts and exchange questions and answers.

## ME11

### What is known about specialist education for palliative medicine?

**Abstract number:** ME11.1

**Abstract type:** Meet the expert

#### What is Known about Specialist Education for Palliative Medicine?

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Where is palliative medicine (PM) a specialty? Is it currently a specialty in any country in Europe? PM professionals have heard such questions before. The worst of all is that often the answers have been vague and we had no clear idea of where and how doctors working full-time in PM could obtain advanced training qualifications.

PM is a new, growing specialty addressed to oncological and non-oncological patients. The session presents the results of a pan-European WHO region (53 countries) expert survey promoted by University of Navarra and Accademia delle Scienze di Medicina Palliativa in Bologna, through a comparative analysis of the programmes on specialisation in PM (published as a Supplement of the EAPC Atlas of Palliative Care in Europe and by the Journal of Pain and Symptoms Management).

In Europe, 18 countries had official specialisation programmes. Advanced training in PM is formally recognised by awarding the qualifications of specialist, sub-specialist or other equivalent qualifications. There is a tendency not to create new specialties in Europe. On average, it takes one to two years of clinical training for formal recognition of the specialisation. There is a tendency to obtain certain posts in health services only with specialisation.

The session will strength the debate on this issue, believing that achieving an official qualification for medical practice represents a huge step forward for palliative care as a discipline, for its formal introduction at universities, and for the defence of professionals and the safety of patients. Although 18 countries is a fair number, there are still 35 countries in which no specialisation process has been established.

The session, along with the scientific publications on this issue, may encourage those health services to progress in this direction. Moreover, the session may explore the interest of pursuing optional quality evaluations in clinical practice or European qualifications.

## ME12

### The science of planning and conducting clinical research in palliative care

**Abstract number:** ME12.1

**Abstract type:** Meet the expert

#### The Science of Planning and Conducting Clinical Research in Palliative Care

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**Planning:** Research in palliative care involves a large amount of money and one or more grant preparations and applications. The process of building a consortium or research team, designing grant application(s) and review(s) and negotiating contracts will take at least a year. When you have mobilised enough resources, researchers have to be recruited and selected, a full protocol written, and all procedures for data collection developed and tested, and you have to prepare and get approval from ethics committees and sometimes from other data protection agencies. At that stage, you have still not collected any data for your study, and another year may have passed. If it is your aim to conduct a full PhD trajectory, this will require three to five years in general. Hence, planning of research in palliative care requires time.

**Successfully conducting:** Research in palliative care is difficult and requires good organisational conditions and personal research knowledge and skills (e.g. creativity, questionnaire development, sampling techniques, statistics, data analyses, scientific writing, multidisciplinary collaboration and team work). Being embedded in an academic multidisciplinary research environment is helpful, and implies supporting services (statistics, IT support, research methods trainings, PhD training etc). Furthermore, researchers need a positive attitude towards research in general, but also towards guidance from their supervisors. Above all, they will need perseverance.

In this meet the expert session, two experienced researchers will exchange and share their experiences with the participants. A number of issues will be highlighted and discussed: What do we have to know before planning a study? How can we optimise the team and research environment? How do we draft a good research protocol? What kind of specific problems and pitfalls are related to research in palliative care, and how can we best deal with these?

## ME13

### The use of steroids in cancer patients with advanced metastatic disease

Abstract number: ME13.1

Abstract type: Meet the expert

#### The Use of Steroids in Cancer Patients with Advanced Metastatic Disease

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The use of steroids to treat multiple symptoms blindly, but based on the assumption of systemic and/or local inflammation, has been very common practice in palliative care. While in individual cases this can be a successful strategy, there is not a good evidence base for this approach. Frequent symptoms in advanced stages of cancer are pain and weight loss/cachexia. A recent RCT of steroids in pain published in JCO 2014, was negative<sup>1</sup>. In cancer cachexia, there are so far limited treatment options. Systemic steroids seem to improve appetite, while weight often is not significantly affected<sup>2</sup>. Unfortunately are side effects of long-term use of steroids severe.

The mechanism of action of steroids versus mechanism of symptoms where steroids are commonly used will be discussed in this session.

1. Paulsen O, Klepstad P, Rosland JH, et al. Efficacy of methylprednisolone on pain, fatigue, and appetite loss in patients with advanced cancer using opioids: a randomised, placebo-controlled, double-blind trial. *J Clin Oncol* 2014; **32**: 3221–8.

2. Yavuzsen T, Davis MP, Walsh D, LeGrand S, Lagman R. Systematic review of the treatment of cancer-associated anorexia and weight loss. *J Clin Oncol* 2005; **23**: 8500–11.

## ME14

### Integrated palliative care

Abstract number: ME14.1

Abstract type: Meet the expert

#### Towards Practice Based Evidence for Integrated Palliative Care

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Integrated care mostly focuses on giving the right care, at the right moment, at the right place, by the right caregiver. Integration can be focused on:

- delivery system integration, namely the barriers and opportunities in regulations and financing within the care system,
- functional integration, involving integration of the organisational structures that facilitate caregiving, eg collaborative teams, and
- clinical integration, aiming at integration at the level of daily care, e.g. joint work protocols.

The World Health Organization (WHO) definition of palliative care addresses integration by referring to psychological and spiritual aspects of patient care, a team approach to address the needs of patients and their families, and the applicability of palliative care early in the course of illness, in conjunction with other therapies. But exactly how elements of this definition can drive integrated care in practice needs further investigation in order to be able to identify good examples and best practices.

Our Integrated Palliative Care project (InsupC; EU FP7) started with reviewing the literature, investigating the integration of palliative care in European guidelines for cancer and non-cancer as well as underlying care models. After that, a taxonomy of integrated palliative care was developed. Currently, an international prospective multicenter patient study is performed in which the experiences of patients, proxies and caregivers with integrated palliative care are investigated. This descriptive study also explores the caregiver network of patients. The data of this study will be mirrored against predefined propositions to identify good examples of integrated palliative care in Europe. Finally, an e-learning module will be developed to give a broad audience access to the results from the project and the lessons learnt.

Abstract number: ME14.2

Abstract type: Meet the expert

#### Building a Taxonomy of Integrated Palliative Care Initiatives: Results from an Expert Focus Group

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**Background:** Empirical evidence suggests that integrated palliative care (IPC) increases the quality of care for terminal patients and supports care givers. Existing IPC initiatives in Europe vary in their design and are hardly comparable. InSuP-C, an EU research project, aimed to build a taxonomy of IPC initiatives applicable across diseases, health care sectors and systems.

**Methods:** The taxonomy of IPC initiatives was developed in cooperation with an international and multidisciplinary focus group. In a consensus conference, experts revised a preliminary taxonomy and adopted the final classification system.

**Results:** Consisting of eight categories, with two to four items each, the taxonomy covers the

process and structure of IPC initiatives. If two items in at least one category apply to an initiative, a minimum level of integration is reached. Categories range from the *type of initiative* (items: *pathway, model or guideline*) to patients' *key contact* (items: *non-PC specialist, PC specialist, GP*). Experts recommended the inclusion of two new categories: *Level of care* (items: *primary, secondary or tertiary*) indicating at which stage palliative care is integrated and *focus of intervention* describing IPC giver's different roles (items: *treating function, advising/consulting or training*) in the care process.

**Conclusion:** The expert focus group broadened the scope of the InSuP-C research team by co-creating a flexible and robust tool to evaluate IPC. Empirical studies will have to investigate how the taxonomy is used in practice and whether it covers the reality of patients in need of palliative care. InSuP-C will use the taxonomy to identify initiatives of IPC that will be examined empirically.

## ME15

### Palliative care in prisons and correctional facilities

Abstract number: ME15.1

Abstract type: Meet the expert

#### Palliative Care in Prisons and Correctional Facilities: Sharing Learning from Practice and Research

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This session will present two examples of prison palliative care from the United Kingdom (UK) and Poland. In the UK, prisoners over the age of 60 are the most rapidly growing section of the prison population, and currently number over 3,500. Many older prisoners have multiple, complex health problems and increasing numbers of them will die in prison. Providing appropriate care for dying prisoners poses substantial challenges for health and discipline staff. Some prisons have begun to respond by developing palliative care in a variety of ways; this presentation will draw on current research in considering recent developments and the implications for staff and prisoners. In Poland, a different initiative is underway in some correctional institutions to train selected prisoners to work as palliative care volunteers, providing care for patients in hospice-palliative care centres. When required, their fellow prisoners are placed in these facilities at the end of their lives. Key elements of this innovative development and research regarding prisoners as hospice volunteers will be presented.

Discussion will cover a range of issues relating to the challenges of providing palliative care in custodial settings and volunteering of prisoners. Suggested discussion topics will include: how the needs of dying prisoners can best be met within the constraints of a custodial environment; how the Polish model of prisoner volunteers might be used in other countries; training and support of prisoners and staff around palliative care; and whether prison can ever be an appropriate place to die.

## ME16

### The future of hospice and palliative care from a volunteering perspective

Abstract number: ME16.1

Abstract type: Meet the expert

#### An Overview of Volunteering in Hospice and Palliative Care in Europe - Similarities and Differences

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**Introduction:** The aim of this session is to report on the work of the EAPC Task Force on Volunteering as it strives to develop a clearer understanding of volunteering and its demography, structure and importance to hospice and palliative care in Europe. Volunteering in many countries in Europe has a close and integral relationship with hospice and palliative care. In some countries, volunteers have been the instigators of services whilst in others there is still tension around whether and how they should be involved. Whilst there is some evidence to suggest that the involvement of volunteers can be transformative, both to their own lives and to the lives of those they support, volunteering in hospice and palliative care is still not well understood.

**Approach:** Drawing upon the literature and early outcomes from Task Force work this session will consider:

- Various factors that influence the complex phenomenon that is volunteering, such as society, culture, demography, legislation and organisational structure and attitudes
- How the expectations of the volunteers themselves are changing
- How regulation can empower or inhibit

Similarities and differences between countries are also discussed in terms of volunteering definitions and constructs, legislative and regulatory requirements, volunteering roles, activities, frameworks and training. Challenges that face volunteering in hospice and palliative care are also briefly considered.

**Conclusion:** As both hospice and palliative care and volunteering continue to develop, the changes in each have the potential to significantly influence the other. As volunteering is to be further developed and sustained in the future, professionals and organisations must have a better understanding of this important component of hospice and palliative care and how the valuable contribution of volunteers can be maximised.

Abstract number: ME16.2

Abstract type: Meet the expert

**The Challenges for Volunteering in Hospice and Palliative Care in Europe. What Does the Further Development of Volunteering Mean to the Hospice and Palliative Care Movement and its Core Values?**

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**Introduction:** Volunteers offer the gift of presence, different skills, experience and time. In some countries, they are, and will continue to be, essential to providing hospice and palliative care services, whilst in some, like Germany and Austria, they are an integral part of a comprehensive highly professional hospice and palliative care setting. However, hospice and palliative care faces many challenges and alongside this a new generation of volunteers have different expectations of volunteering and some want to use their skills in different and more meaningful ways.

**Approach:** Based on the work of the EAPC Task Force on Volunteering in Hospice and Palliative Care, the aim of this session is to explore some of the challenges for volunteering and volunteers in hospice and palliative care by considering:

- How well volunteering values and principles are understood and how closely these relate to hospice and palliative care values
- The place of volunteers within the team and the relationships between volunteers and paid staff
- How to match the changing expectations of volunteers with the changing needs of organisations

This session will also reflect on how well the value of volunteering is recognised and whether enabling volunteers to use their skills to best advantage could add to the quality of life for patients and families. Often, the social support that volunteers can offer to patients and their loved ones is an important aspect of holistic care. How well is this considered as part of a package of care?

**Conclusion:** If volunteering is to be developed successfully in the future we must be able to match the changing needs of our patients, their families and our organisations with the changing expectations of the volunteers of tomorrow. If we succeed in doing this, we will retain the large and important contribution made by volunteers and may be able to embrace fully the values of hospice and palliative care.

# Meet the Expert Sessions

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- ME13** The use of steroids in cancer patients with advanced metastatic disease
- ME14** Integrated palliative care
- ME15** Palliative care in prisons and correctional facilities
- ME16** The future of hospice and palliative care from a volunteering perspective



## ME01

### Family carers: evidence based practice

**Abstract number:** ME01.1

**Abstract type:** Meet the expert

#### Family Carers: Evidence Based Practice

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Providing support for family carers is a core element of palliative care provision. However, systematic reviews have highlighted the need for more evidence based interventions to assist family carers.

This expert session will focus on:

- (1) Why more needs to be done to improve family carer support
- (2) Challenges faced by health professionals associated with supporting family carers
- (3) Examples of evidence based family carer.

## ME02

### Electronic palliative care coordination and decision support systems

**Abstract number:** ME02.1

**Abstract type:** Meet the expert

#### EIR – An Electronic Decision Support Tool in Oncology

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The European Palliative Care Research Centre has recently conducted a clinical trial (Combat study) employing computerised clinical decision support tools developed in close collaboration with software engineers. Patients completed an electronic questionnaire on an iPad. This data was wirelessly transferred to the desktop PC employed by the clinician and this system also provided electronic decision support for the clinician. The results of this study will be published during 2014. We have further developed this software tool, called EIR, to the next level. In EIR, patients complete an electronic questionnaire by smart phone, tablets or computers. This data is transferred and visualised on the desktop PC applied by the physician in a more intuitive and user friendly style compared to the initial version of the software tool. Additionally, we have developed more complex decision support tools. The content of the talk will focus on the advantages and pitfalls of computerised clinical decision support based on the EIR software tool.

**Abstract number:** ME02.2

**Abstract type:** Meet the expert

#### Coordinate My Care (CMC): A Pan London Clinical Service

*Riley J.L.*

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CMC is a clinical service created by NHS clinicians, for NHS patients. It offers a digital Personalised Urgent Care Plan to patients living in London and Surrey Downs. CMC was set up to improve the identification and coordination of care for palliative care patients who depend on multidisciplinary teams, across acute, community and the voluntary sectors. It is now offered to all vulnerable patients with complex needs. All patients consent to having a CMC care plan, or they may be consented in best interest if they lack capacity. CMC can be accessed by all the urgent care services 24/7, thus vital information is accessible during the out of hours period that represents two thirds of the week. When a CMC urgent care plan is created the Urgent care services are immediately alerted. These services include 111, the out of Hours GP service covering the patient, the patient's own GP and the Ambulance service. Currently 19,817 patients have CMC urgent care plans CMC records, of whom 7,970 have died. In England 54% of patients die in hospital<sup>[1]</sup>, however, for those with a CMC record the number drops to the lowest nationally at 17% dying in hospital and 79% dying in their preferred place. On average, there is a £2,100 saving per patient with a CMC plan by reducing unnecessary emergency admissions and hospital transfer costs<sup>[2]</sup>. Patients will soon be able to access their care plans on their smart phones. CMC thus improves quality of care and decreases costs.

#### References:

- [1] National End of Life Care Intelligence Network (2008-10)
- [2] Source: Frontier Economic Evaluation Report December 2014

## ME03

### Palliative care for people with heart failure

**Abstract number:** ME03.1

**Abstract type:** Meet the expert

#### Unmet Needs in Patients with Heart Failure at End of Life

*Currow D.C.*

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Heart failure is highly prevalent, particularly in resource rich countries. Throughout the world, heart failure without an identifiable aetiology carries an extremely poor prognosis despite the medications that are available to manage heart failure and the option in some settings of even considering transplantation.

The needs of people with heart failure are not dissimilar to any other group within the community - symptom control is crucial, optimising function including mobility is important and ensuring that the other domains that are valued at the end of life are facilitated by excellent attention to detail.

Likewise, caregivers of people with heart failure have very similar needs to other caregivers for people at the end of life. This suggests that there is a 'final common pathway' leading to death that generates similar issues for patients and their caregivers almost irrespective of the underlying disease process.

Cachexia, fatigue, dyspnoea, pain and sleep disturbance are all prominent symptoms, however much more work needs to be done to understand their impact longitudinally in heart failure.

The next 10 years will bring enormous opportunity to understand in more detail through rigorous research the issues faced by people with heart failure as their life limiting illness.

**Abstract number:** ME03.2

**Abstract type:** Meet the expert

#### Patients with Implanted Electronic and Mechanical Devices Approaching Death

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Cardiovascular implantable electronic devices (CIED) encompass pacemakers, implantable cardioverter defibrillators (ICDs) and cardiac resynchronisation therapy (CRT) devices. Some of them function continuously; others monitor rhythm, and only intervene if the device recognises rhythm disturbances. These devices change the trajectory not only of life, but also death, often in a painful manner. The rate of ICD implantations exceeds 30,000 per month worldwide. Every person with a device will eventually die, the majority having a potentially recognisable terminal phase of life. Modification of the activity of the device may improve the quality of dying. Decision-making regarding modification device activity confronts patients, relatives and health care professionals with many challenges. The possibility of modifying device activity in situations where potential intervention no longer fits possible goals should be discussed in advance, optimally while obtaining consent for device implantation. Currently, less than 1% of patients with ICDs draw up advance directives embracing issues in respect of ICD activity. Most patients with an ICD approach death with a fully active device. About 20% of them experience shock therapies in the last days or even hours of life. The deactivation if not performed electronically, can be done in an emergent manner using a magnet.

Implantable mechanical devices – ventricular assist devices (VADs) or artificial hearts – are becoming an increasingly common alternative to heart transplantation. They however, generate difficult end-of-life dilemmas. The appearance of a lethal pathophysiology defines permissibility of withdrawing device support. Turning off a VAD is emotionally challenging, because it is a life-terminating intervention.

The European Association for Palliative Care and Heart Failure Association have created a Joint Task Force to address palliative issues in adults with advanced heart failure.

## ME04

### Developing the relationship between palliative care and neurology

**Abstract number:** ME04.1

**Abstract type:** Meet the expert

#### Developing the Relationship between Palliative Care and Neurology

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A joint working group of the European Association for Palliative Care and the European Federation of Neurological Societies (now the European Academy of Neurology) has produced a Consensus paper on the available evidence for the palliative care in progressive neurological disease, including ALS, multiple sclerosis, Parkinson's disease, stroke and primary brain tumours.

The seven main areas of recommendation are:

1. Palliative care should be considered early in the disease trajectory.
2. The assessment and care should be provided by a multidisciplinary team approach, with

access to specialist palliative care.

3. Communication should be open with patients and families and advance care planning is recommended. This should be as soon as possible in view of the likelihood of difficulties in communication and the development of cognitive changes in several neurological disorders.
  4. Symptoms – physical and psychosocial – should be managed actively and appropriately.
  5. Care needs should be assessed and carers supported before and after death. Professional carers should receive education, support and supervision to reduce the risks of emotional exhaustion.
  6. There should be repeated and continued discussion about end of life issues and discussion of patients' wishes and aims. The recognition of the deterioration and dying phase will allow appropriate management and intervention.
  7. Palliative care principles should be included with the training and continuing medical education of neurologists and palliative care professionals should understand the issues for neurological patients.
- These recommendations have been developed with the aim of improving knowledge and understanding of palliative care for patients with progressive neurological disease. There is now the opportunity to look at developing the relationship between palliative medicine and neurology to ensure that these principles are extended as widely as possible to support patients and their carers.

## ME05

How to implement evidence based medicine (EBM) into clinical practice. A clinical and health policy perspective

**Abstract number:** ME05.1

**Abstract type:** Meet the expert

### How to Implement Evidence Based Medicine (EBM) into Clinical Practice: A Clinical and Health Policy Perspective

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Evidence-based practice (EBP) is the conscientious and judicious use of current best evidence in conjunction with clinical expertise and patient values to guide health care decisions. Best evidence includes empirical evidence from systematic literature reviews, randomised controlled trials, descriptive and qualitative research. Lower levels of evidence, such as case reports and expert opinion, are also used. More than 20 years have passed since an evidence-based medicine working group announced this "new paradigm" for teaching and practising clinical medicine. They proposed tradition, anecdote, and theoretical reasoning from basic sciences would be replaced by evidence from high quality studies, in combination with clinical expertise and the needs and wishes of patients. However, implementing evidence-based medicine in palliative care practice and policies encounters challenges including: level of available research evidence, judgement of evidence, keeping up to date, how evidence is balanced with clinical expertise and patient values, too much evidence, distortion of the brand and the suitability for those with multi-morbidity and/or approaching the end of life.

This 'meet the expert' session will discuss how approaches in evidence-based medicine compare with the seven common alternatives: eminence based medicine, vehemence-based medicine, eloquence-based medicine, providence-based medicine, diffidence-based medicine, nervousness-based medicine and confidence-based medicine. The session will then go on to debate how 'fit for purpose' evidence-based medicine is for palliative care and the implementation of 'real' evidence-based medicine into practice and policy. Participants are encouraged to bring current challenges for discussion.

## ME06

Quality improvement in palliative care with the help of indicators: the EU-funded IMPACT project

**Abstract number:** ME06.1

**Abstract type:** Meet the expert

### IMPACT: Improving the Organisation of your Palliative Care Setting

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**Background:** In the past decade, several sets of quality indicators (QIs) for palliative care have been developed. Yet, mostly these indicators are meant for one type of setting (e.g. intensive care units), one patient category (patients with cancer), focus on clinical outcome or clinical processes (e.g. pain level), are limited to the terminal phase and are developed in one specific country. Besides, just developing QIs does not change practice. A structured improvement project is needed.

**Methods:** We took account of all above-mentioned considerations in our European IMPACT project, in which professionals in palliative care and researchers collaborated. We performed a literature study, focus group interviews, a modified Rand Delphi procedure, a pilot with improvement projects in 40 settings in five European countries (NL, D, I, No, UK) and a nominal group session.

**Results:** We developed of models for the organisation of palliative care, developed QIs for the organisation of palliative care settings, and strategies to improve the organisation of the setting (primary care, hospice, nursing home or hospital). The QIs were used to select topics and aims for quality improvement projects, and to monitor change, in several types of settings and for several patient categories in five countries, and anticipated further dissemination and implementation of our tools.

**Conclusions:** Theory and practice were combined in this project, as well as cancer and

dementia palliative care. We did not stop after QIs were developed, but also developed strategies to use them for quality improvement. With the results of this project we provide scientifically sound, practice-friendly tools to improve the organisation of settings that deliver palliative care all over Europe.

**Abstract number:** ME06.2

**Abstract type:** Meet the expert

### Using Quality Indicators for Service Improvement: An Example from Five European Countries

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The EU-funded multinational IMPACT study has identified quality indicators to improve the organisation of palliative care, not only of patients with cancer but also for those with dementia. The set of 25 quality indicators has been consented by experts from five European countries and includes, for example, access to specialist palliative care, regular assessment of pain and other symptoms, accessibility of opioids and other analgesics, coordinated delivery of health and social care by a designated contact person, regular multidisciplinary team meetings or provision of bereavement support for family care givers as well as for staff.

The indicator set was tested in a sample of 37 services (nursing homes, hospital services, hospices and primary care services) in the five participating countries. For most, a specialised PC team is accessible (25); only 3 did not have access to expert advice in PC. Even though many services offered bereavement support to patient families and team members, standardised procedures were often lacking. Opioids and other analgesics were available around the clock in most services (29).

The services selected specific indicators for the next step of the quality improvement project, and developed specific strategies to implement these indicators. Evaluation of these strategies demonstrated that the implementation required specific dedicated resources, as well as support from the administrative level of the organisation.

In conclusion, the indicator set was found useful by the participating services. The project instigated lively discussions of organisational improvement needs and on the applicability of quality indicators in the surveyed services.

## ME07

European Palliative Care Academy – Leadership Course

**Abstract number:** ME07.1

**Abstract type:** Meet the expert

### The European Palliative Care Academy: Creating Leaders in Palliative and End of Life Care

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Across Europe, palliative care is an increasingly important public health issue due to population ageing, the increasing number of older people dying from advanced diseases, and insufficient attention to their complex needs, and their families. Developing a highly skilled workforce is critical if we are to best serve this population. The European Palliative Care Academy represents a joint venture to train emerging leaders in palliative care across Europe to advance palliative care, and to address future challenges in this important field. Generously funded by the Robert Bosch Foundation, it comprises four highly acclaimed European academic centres: University Hospital Cologne (Germany), Nicolaus Copernicus University in Torun (Poland), Hospice Casa Sperantei in Brasov (Romania) and King's College London (United Kingdom). In this session we will explain the philosophy and content of this exciting new course, describe the successes of our first cohort of course participants, and address any questions from prospective students.

## ME08

Core competencies in palliative care social work: key points from the EAPC White Paper; The roles and tasks of palliative care social workers: their views

**Abstract number:** ME08.1

**Abstract type:** Meet the expert

### Core Competencies in Palliative Care Social Work: Key Points from the EAPC White Paper; The Roles and Tasks of Palliative Care Social Workers: Their Views

*Hughes S<sup>1</sup>, Bitschnau K.W.<sup>2</sup>*

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The EAPC Task Force on Palliative Care Social Work was set up to examine the diverse roles and tasks of palliative care social workers across Europe. This task was conceived as a prelude to developing core curricula for the education of all social workers with a palliative care remit. To that end, members of the Task Force consulted with social workers across the European continent, looked at the development and history of social work as a specialism within palliative care - where this had occurred, and considered the emerging literature on the role, particularly that from North America but also further afield. The resulting paper:



Core competencies for palliative care social in Europe: an EAPC White Paper, was published in two parts in recent months. A White Paper is essentially a discussion document meant to stimulate debate and is not intended as the final word on the subject. In his session, Sean Hughes, one of the co-authors of the paper, will begin by outlining some of the key concepts within the article and highlight some areas for debate and consideration. Karl Bitschnau will follow with a short presentation on more recent developments led by the Task Force, in surveying social worker views on their palliative care tasks and roles. He will summarise key findings from this work and will conclude with an outline of next steps in the process. We anticipate that these two presentations will stimulate much discussion and will therefore allow time in this short session for comment, questions and participation from the audience. This session will be of particular interest to social workers, but in a spirit of collegiality we welcome colleagues from all our partner disciplines to join us in our deliberations.

## ME09

### Global palliative care development and the WHA resolution on strengthening palliative care

**Abstract number:** ME09.1

**Abstract type:** Meet the expert

#### Global Palliative Care Development and the WHA Resolution on Strengthening Palliative Care

*Connor S.R.<sup>1</sup>, Mosoiu D.<sup>2</sup>*

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In this expert session participants will hear about the latest developments and plans for the WHO to implement the recent resolution "Strengthening of Palliative Care as a Component of Comprehensive Care Throughout the Life Course." This resolution, passed at the World Health Assembly (WHO's governing body) last May, is a major turning point in the global development of palliative care. Countries agreed to call on themselves to include palliative care in all major health policies, to improve the availability of essential palliative care medications, to bring palliative care education into health care professional training at all levels, to begin to fund palliative care program implementation, to do more research on palliative care and more. WHO itself is called on to provide guidance to countries on palliative care and to develop clinical guidelines as well as many technical assistance documents to help countries to strengthen palliative care. An Ad Hoc Technical Advisory Group has been formed to assist WHO in plans for implementation and a strategic plan has been developed to guide work in the coming years. Learn what other countries are doing, and how you can use this opportunity to spur palliative care development in your own country, how to monitor progress and how to use the *Global Atlas of Palliative Care at the End of Life* to benchmark progress.

## ME10

### Improving spiritual care in clinical practice

**Abstract number:** ME10.1

**Abstract type:** Meet the expert

#### Improving Spiritual Care in Clinical Practice

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In this session, we begin with a short introduction on the state of the art of spiritual care in clinical practice as observed by the spiritual care taskforce of the EAPC. Subsequently, we will present some examples of how to improve spiritual care in clinical practice. Those who are present are invited to share their experiences from different contexts and exchange questions and answers.

## ME11

### What is known about specialist education for palliative medicine?

**Abstract number:** ME11.1

**Abstract type:** Meet the expert

#### What is Known about Specialist Education for Palliative Medicine?

*Bolognesi D.<sup>1</sup>, Centeno C.<sup>2</sup>*

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Where is palliative medicine (PM) a specialty? Is it currently a specialty in any country in Europe? PM professionals have heard such questions before. The worst of all is that often the answers have been vague and we had no clear idea of where and how doctors working full-time in PM could obtain advanced training qualifications.

PM is a new, growing specialty addressed to oncological and non-oncological patients. The session presents the results of a pan-European WHO region (53 countries) expert survey promoted by University of Navarra and Accademia delle Scienze di Medicina Palliativa in Bologna, through a comparative analysis of the programmes on specialisation in PM (published as a Supplement of the EAPC Atlas of Palliative Care in Europe and by the Journal of Pain and Symptoms Management).

In Europe, 18 countries had official specialisation programmes. Advanced training in PM is formally recognised by awarding the qualifications of specialist, sub-specialist or other equivalent qualifications. There is a tendency not to create new specialties in Europe. On average, it takes one to two years of clinical training for formal recognition of the specialisation. There is a tendency to obtain certain posts in health services only with specialisation.

The session will strength the debate on this issue, believing that achieving an official qualification for medical practice represents a huge step forward for palliative care as a discipline, for its formal introduction at universities, and for the defence of professionals and the safety of patients. Although 18 countries is a fair number, there are still 35 countries in which no specialisation process has been established.

The session, along with the scientific publications on this issue, may encourage those health services to progress in this direction. Moreover, the session may explore the interest of pursuing optional quality evaluations in clinical practice or European qualifications.

## ME12

### The science of planning and conducting clinical research in palliative care

**Abstract number:** ME12.1

**Abstract type:** Meet the expert

#### The Science of Planning and Conducting Clinical Research in Palliative Care

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**Planning:** Research in palliative care involves a large amount of money and one or more grant preparations and applications. The process of building a consortium or research team, designing grant application(s) and review(s) and negotiating contracts will take at least a year. When you have mobilised enough resources, researchers have to be recruited and selected, a full protocol written, and all procedures for data collection developed and tested, and you have to prepare and get approval from ethics committees and sometimes from other data protection agencies. At that stage, you have still not collected any data for your study, and another year may have passed. If it is your aim to conduct a full PhD trajectory, this will require three to five years in general. Hence, planning of research in palliative care requires time.

**Successfully conducting:** Research in palliative care is difficult and requires good organisational conditions and personal research knowledge and skills (e.g. creativity, questionnaire development, sampling techniques, statistics, data analyses, scientific writing, multidisciplinary collaboration and team work). Being embedded in an academic multidisciplinary research environment is helpful, and implies supporting services (statistics, IT support, research methods trainings, PhD training etc). Furthermore, researchers need a positive attitude towards research in general, but also towards guidance from their supervisors. Above all, they will need perseverance.

In this meet the expert session, two experienced researchers will exchange and share their experiences with the participants. A number of issues will be highlighted and discussed: What do we have to know before planning a study? How can we optimise the team and research environment? How do we draft a good research protocol? What kind of specific problems and pitfalls are related to research in palliative care, and how can we best deal with these?

## ME13

### The use of steroids in cancer patients with advanced metastatic disease

Abstract number: ME13.1

Abstract type: Meet the expert

#### The Use of Steroids in Cancer Patients with Advanced Metastatic Disease

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The use of steroids to treat multiple symptoms blindly, but based on the assumption of systemic and/or local inflammation, has been very common practice in palliative care. While in individual cases this can be a successful strategy, there is not a good evidence base for this approach. Frequent symptoms in advanced stages of cancer are pain and weight loss/cachexia. A recent RCT of steroids in pain published in JCO 2014, was negative<sup>1</sup>. In cancer cachexia, there are so far limited treatment options. Systemic steroids seem to improve appetite, while weight often is not significantly affected<sup>2</sup>. Unfortunately are side effects of long-term use of steroids severe.

The mechanism of action of steroids versus mechanism of symptoms where steroids are commonly used will be discussed in this session.

1. Paulsen O, Klepstad P, Rosland JH, et al. Efficacy of methylprednisolone on pain, fatigue, and appetite loss in patients with advanced cancer using opioids: a randomised, placebo-controlled, double-blind trial. *J Clin Oncol* 2014; **32**: 3221–8.

2. Yavuzsen T, Davis MP, Walsh D, LeGrand S, Lagman R. Systematic review of the treatment of cancer-associated anorexia and weight loss. *J Clin Oncol* 2005; **23**: 8500–11.

## ME14

### Integrated palliative care

Abstract number: ME14.1

Abstract type: Meet the expert

#### Towards Practice Based Evidence for Integrated Palliative Care

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Integrated care mostly focuses on giving the right care, at the right moment, at the right place, by the right caregiver. Integration can be focused on:

- delivery system integration, namely the barriers and opportunities in regulations and financing within the care system,
- functional integration, involving integration of the organisational structures that facilitate caregiving, eg collaborative teams, and
- clinical integration, aiming at integration at the level of daily care, e.g. joint work protocols.

The World Health Organization (WHO) definition of palliative care addresses integration by referring to psychological and spiritual aspects of patient care, a team approach to address the needs of patients and their families, and the applicability of palliative care early in the course of illness, in conjunction with other therapies. But exactly how elements of this definition can drive integrated care in practice needs further investigation in order to be able to identify good examples and best practices.

Our Integrated Palliative Care project (InsupC; EU FP7) started with reviewing the literature, investigating the integration of palliative care in European guidelines for cancer and non-cancer as well as underlying care models. After that, a taxonomy of integrated palliative care was developed. Currently, an international prospective multicenter patient study is performed in which the experiences of patients, proxies and caregivers with integrated palliative care are investigated. This descriptive study also explores the caregiver network of patients. The data of this study will be mirrored against predefined propositions to identify good examples of integrated palliative care in Europe. Finally, an e-learning module will be developed to give a broad audience access to the results from the project and the lessons learnt.

Abstract number: ME14.2

Abstract type: Meet the expert

#### Building a Taxonomy of Integrated Palliative Care Initiatives: Results from an Expert Focus Group

Ewert B.<sup>1</sup>, van Wijngaarden J.<sup>2</sup>, Radbruch L.<sup>1</sup>

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**Background:** Empirical evidence suggests that integrated palliative care (IPC) increases the quality of care for terminal patients and supports care givers. Existing IPC initiatives in Europe vary in their design and are hardly comparable. InSuP-C, an EU research project, aimed to build a taxonomy of IPC initiatives applicable across diseases, health care sectors and systems.

**Methods:** The taxonomy of IPC initiatives was developed in cooperation with an international and multidisciplinary focus group. In a consensus conference, experts revised a preliminary taxonomy and adopted the final classification system.

**Results:** Consisting of eight categories, with two to four items each, the taxonomy covers the

process and structure of IPC initiatives. If two items in at least one category apply to an initiative, a minimum level of integration is reached. Categories range from the *type of initiative* (items: *pathway, model or guideline*) to patients' *key contact* (items: *non-PC specialist, PC specialist, GP*). Experts recommended the inclusion of two new categories: *Level of care* (items: *primary, secondary or tertiary*) indicating at which stage palliative care is integrated and *focus of intervention* describing IPC giver's different roles (items: *treating function, advising/consulting or training*) in the care process.

**Conclusion:** The expert focus group broadened the scope of the InSuP-C research team by co-creating a flexible and robust tool to evaluate IPC. Empirical studies will have to investigate how the taxonomy is used in practice and whether it covers the reality of patients in need of palliative care. InSuP-C will use the taxonomy to identify initiatives of IPC that will be examined empirically.

## ME15

### Palliative care in prisons and correctional facilities

Abstract number: ME15.1

Abstract type: Meet the expert

#### Palliative Care in Prisons and Correctional Facilities: Sharing Learning from Practice and Research

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This session will present two examples of prison palliative care from the United Kingdom (UK) and Poland. In the UK, prisoners over the age of 60 are the most rapidly growing section of the prison population, and currently number over 3,500. Many older prisoners have multiple, complex health problems and increasing numbers of them will die in prison. Providing appropriate care for dying prisoners poses substantial challenges for health and discipline staff. Some prisons have begun to respond by developing palliative care in a variety of ways; this presentation will draw on current research in considering recent developments and the implications for staff and prisoners. In Poland, a different initiative is underway in some correctional institutions to train selected prisoners to work as palliative care volunteers, providing care for patients in hospice-palliative care centres. When required, their fellow prisoners are placed in these facilities at the end of their lives. Key elements of this innovative development and research regarding prisoners as hospice volunteers will be presented.

Discussion will cover a range of issues relating to the challenges of providing palliative care in custodial settings and volunteering of prisoners. Suggested discussion topics will include: how the needs of dying prisoners can best be met within the constraints of a custodial environment; how the Polish model of prisoner volunteers might be used in other countries; training and support of prisoners and staff around palliative care; and whether prison can ever be an appropriate place to die.

## ME16

### The future of hospice and palliative care from a volunteering perspective

Abstract number: ME16.1

Abstract type: Meet the expert

#### An Overview of Volunteering in Hospice and Palliative Care in Europe - Similarities and Differences

Scott R.

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**Introduction:** The aim of this session is to report on the work of the EAPC Task Force on Volunteering as it strives to develop a clearer understanding of volunteering and its demography, structure and importance to hospice and palliative care in Europe. Volunteering in many countries in Europe has a close and integral relationship with hospice and palliative care. In some countries, volunteers have been the instigators of services whilst in others there is still tension around whether and how they should be involved. Whilst there is some evidence to suggest that the involvement of volunteers can be transformative, both to their own lives and to the lives of those they support, volunteering in hospice and palliative care is still not well understood.

**Approach:** Drawing upon the literature and early outcomes from Task Force work this session will consider:

- Various factors that influence the complex phenomenon that is volunteering, such as society, culture, demography, legislation and organisational structure and attitudes
- How the expectations of the volunteers themselves are changing
- How regulation can empower or inhibit

Similarities and differences between countries are also discussed in terms of volunteering definitions and constructs, legislative and regulatory requirements, volunteering roles, activities, frameworks and training. Challenges that face volunteering in hospice and palliative care are also briefly considered.

**Conclusion:** As both hospice and palliative care and volunteering continue to develop, the changes in each have the potential to significantly influence the other. As volunteering is to be further developed and sustained in the future, professionals and organisations must have a better understanding of this important component of hospice and palliative care and how the valuable contribution of volunteers can be maximised.

Abstract number: ME16.2

Abstract type: Meet the expert

**The Challenges for Volunteering in Hospice and Palliative Care in Europe. What Does the Further Development of Volunteering Mean to the Hospice and Palliative Care Movement and its Core Values?**

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**Introduction:** Volunteers offer the gift of presence, different skills, experience and time. In some countries, they are, and will continue to be, essential to providing hospice and palliative care services, whilst in some, like Germany and Austria, they are an integral part of a comprehensive highly professional hospice and palliative care setting. However, hospice and palliative care faces many challenges and alongside this a new generation of volunteers have different expectations of volunteering and some want to use their skills in different and more meaningful ways.

**Approach:** Based on the work of the EAPC Task Force on Volunteering in Hospice and Palliative Care, the aim of this session is to explore some of the challenges for volunteering and volunteers in hospice and palliative care by considering:

- How well volunteering values and principles are understood and how closely these relate to hospice and palliative care values
- The place of volunteers within the team and the relationships between volunteers and paid staff
- How to match the changing expectations of volunteers with the changing needs of organisations

This session will also reflect on how well the value of volunteering is recognised and whether enabling volunteers to use their skills to best advantage could add to the quality of life for patients and families. Often, the social support that volunteers can offer to patients and their loved ones is an important aspect of holistic care. How well is this considered as part of a package of care?

**Conclusion:** If volunteering is to be developed successfully in the future we must be able to match the changing needs of our patients, their families and our organisations with the changing expectations of the volunteers of tomorrow. If we succeed in doing this, we will retain the large and important contribution made by volunteers and may be able to embrace fully the values of hospice and palliative care.

# Free Communication sessions

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## FC01 Family caregivers

Abstract number: FC01.1  
Abstract type: Oral

### 'Struggling for Normal': Self-management of Family Caregivers in Palliative Home Care. A Longitudinal Qualitative Study

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**Background:** Family caregivers play a key role in palliative home care for persons with advanced cancer. Research has shown numerous burdens and strains of family caregiving, nevertheless families are dealing day-to-day with terminal illness at home. There is limited evidence on what enables caregivers to care for a palliative patient at home. The concept of self-management may well apply to the context of palliative home care.

**Aims:** This study aims to understand family caregivers' experiences and self-management strategies in palliative home care over time.

**Methods:** A qualitative longitudinal design was chosen. Data collection consisted of serial in-depth interviews with family caregivers during ongoing palliative home care and after the death of the patient. Caregivers were recruited by specialist palliative care services. A total of 24 interviews and field notes provided data for the analysis of 10 trajectories, applying a case reconstruction methodology.

**Results:** Palliative home care disrupts everyday life of families by being unpredictable to them. To deal with uncertainty, family caregivers aim to maintain or regain normality. A key self-management strategy in this process is taking responsibility for all aspects of caring. As part of this, restructuring daily life by introducing revised routines is an important strategy. This includes balancing family relationships and job requirements. In an ongoing process of 'attention' and 'adaptation', caregivers seek to gain confidentiality in dealing with terminal illness. Maintaining autonomy is an important request.

**Conclusions:** Fostering self-management means to actively recognise the endeavours of family caregivers to struggle for normality and to refer to their resources and problem solving skills. Palliative home care should adopt a family-centred approach.

Abstract number: FC01.2  
Abstract type: Oral

### Family Carers' Support Needs in End-of-Life Care: Translation into Practice

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**Background:** The Carer Support Needs Assessment Tool (CSNAT) encompasses the physical, psychological, social, practical, financial and spiritual support needs that government policies in many countries emphasise should be assessed, addressed and delivered to family carers (FCs) during end-of-life care.

**Objectives:** To describe the experience of FCs and nurses of terminally ill people with the CSNAT intervention in home based specialist palliative care.

**Methods:** This study was conducted during 2012–14 in Silver Chain Hospice Care Service in Western Australia. 233 FCs and 44 nurses participated in trialing the CSNAT intervention using a stepped wedge cluster design (which included 89 in the control group). FCs' feedback was obtained via telephone interviews and nurses via a questionnaire. Data were subjected to a thematic content analysis.

**Results:** The overwhelming majority of FCs found the CSNAT needs assessment process validating, reassuring and empowering. They appreciated the value of the intervention in systematically engaging them in conversations about their needs, priorities and solutions which were timely and responsive to their needs. The majority of nurses reported that using the CSNAT was effective at eliciting FC concerns, prompted them to review/assess the support and recommended integrating it in routine practice.

**Conclusions:** CSNAT provides a formal structure to facilitate discussions with FCs to enable needs to be addressed in a timely manner. Such discussions will provide service providers with an evidence base for the development of their support services, ensuring the new or improved services are designed to meet the explicit needs of FCs and by consequence relieving their strain and distress.

(Funded by an Australian Research Council Linkage Grant and Silver Chain).

Abstract number: FC01.3  
Abstract type: Oral

### Family Members' Sense of Support within the Family in the Palliative Care Context – What Are the Influencing Factors?

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**Background:** Mutual support within the family can be a valuable resource to the members of the family when confronted with impending death.

**Aim:** Based on a family system approach, the aim was to evaluate which factors are associated with family members' sense of support within the closest family in the palliative care context.

**Methods:** We interviewed 231 adult family members (76% of eligible family members) of adult patients who had non-curable disease with an expected short-term survival from six

palliative home care units. The individual factors were evaluated using GLM (generalised linear model; ordinal multinomial distribution and logit link).

**Results:** The family members' ratings of their sense of support within the family ranged from 1 (never) to 6 (always), with a mean value of 4.82 (SD 1.11). The family members who less frequently sensed such support were mostly characterised by: living in a family and with children, and not being a pensioner. They rated lower quality of life, higher attachment anxiety, more often anxiety, pain or discomfort. Furthermore, family members who less frequently sensed support within the closest family rated higher negative impact and lower positive value of being a family member to a severely ill person, and that they received worse quality of support. They also reported more difficulty in the possibility of respite, less often sense of security with the palliative care provided, less often support for themselves as well as for the patient from family, relatives and friends other than the closest ones. The patients with those family members who less frequently sensed support within the closest family were more often living with children, and had changed behaviour.

**Conclusions:** The identified factors may help palliative care teams to identify family members at risk of perceiving a low sense of support within the family and to alleviate suffering.

Abstract number: FC01.4  
Abstract type: Oral

### Family Caregiver Coping in End of Life Cancer Care: Results from a Mixed Methods Multi-site Study in Palliative Home Care

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**Background:** Caregiving places a heavy burden on family caregivers (FCGs). Yet research shows that some FCGs cope relatively well with caregiving whereas others do not. There has been little research examining why some FCGs seem to deal better with caregiving at home than others.

**Aims:** To understand the factors that influence FCGs' ability to provide end of life cancer care at home and to determine predictors of quality of life (QOL) and depression.

**Methods:** A mixed methods study including semi-structured interviews with 29 current caregivers and a structured questionnaire administered to 317 FCGs recruited from 3 urban settings in Canada. Analyses were guided by a theoretical model to test the relationships between primary and secondary stress mediators, primary and secondary appraisals and our primary outcomes of QOL and depression. Statistically significant variables were entered in a hierarchical regression analysis.

**Results:** High care demands are significantly associated with lower QOL and higher levels of depression, especially for FCGs appraised as having low levels of resilience and optimism. QOL was higher for FCGs who were resilient and optimistic, who had good quality family relationships, and who had a strong sense of cohesiveness within the family. FCGs who were satisfied with health services and felt better prepared for caregiving had significantly higher QOL scores than FCGs who were not satisfied or not prepared. Findings also suggest greater depressive symptoms and lower QOL among FCGs who had health problems, felt that caregiving interfered with lifestyle and perceived caregiving as stressful.

**Conclusions:** Findings provide insights into FCG characteristics related to personality, family functioning, and family caregiving and patient illness experiences, which can help guide interventions for FCGs at risk of depressive symptoms and reduced QOL in the context of home-based palliative care.

**Funding:** Canadian Cancer Society Research Institute

Abstract number: FC01.5  
Abstract type: Oral

### Family Caregivers' Preferences for Place of Care for Patients at the End of Life: Implications of a Systematic Review for Policy and Practice

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**Background:** Government policies stress the importance of patients' and their families' preferences when deciding on place of care at the end of life. While patients' preferences are well documented and often favour care at home, the preferences of their families are less well known. Due to the nature of long-term conditions, families are often involved in the care of patients at the end of life. To ensure families receive appropriate support to care for patients in their preferred location, it is important to understand family caregivers' preferences.

**Aims:** To systematically search and synthesise the qualitative literature exploring family caregivers' preferences and perceptions surrounding place of care of their relatives at the end-of-life.

**Methods:** Ten databases and key palliative care journals reference lists were searched in January 2014. Article titles, abstracts and full-text papers were reviewed by two researchers and included studies (n=18) were appraised for quality. The data were thematically synthesised.

**Results:** Family caregivers reported feeling obligated by patients and healthcare professionals to provide care for their relative at home. Most studies focused on care at home, which was considered the preferred place of care. Hospitals were considered unsuitable for palliative care, with hospices favoured. However, preferences could change over time and hospitals preferred, in particular if the patient experienced distressing symptoms. Feeling unprepared and unsupported made caregiving challenging, while resilience and good family relationships eased the process.

**Conclusions:** It is vital to ensure that family caregivers feel supported during the decision making process and, if home care is favoured, are then adequately supported by healthcare professionals to assume the caring role. It is thus essential to consider what interventions work best to support relatives caring for patients at home at the end of life.



Abstract number: FC01.6

Abstract type: Oral

**Forging Relationships with Families at Sunset and Dawn**

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**Background:** Family and carers are an integral part of palliative care (PC). More information is needed to address their needs as little is known about what makes them seek support from specialist services. Our 24 hour PC platform gives support both to families and professionals involved in the care and treatment of patients with PC needs. It is placed and logistically supported within the regional pre-hospital emergency care coordinating centre. **Aims:** This study analyses all the calls received, explores the reason behind and the answer given to the team, focusing on family activity.

**Methods:** A retrospective study call data collected between December 2010 and September 2014.

**Results:** 64919 calls were recorded, from which 55% were made by relatives of patients with PC needs. 39% called overnight (from 9pm to 9am). 58.8% were related to symptom control issues, 7.5% related to family support in the patients last days of life, or feeling lost or doubting how to act in some cases. Death certification 5.7% with three peaks at 6–7am, 5 and 9–10 pm. With appropriate input with listening and counselling, most of the calls (53.3%) were resolved within the call without further action.

**Discussion:** Over time, calls made by relatives have increased as the public becomes aware of our existence. Many of these calls were made overnight, when primary care teams and traditional palliative care teams don't work. Most calls relate to emerging difficult situations. Although specialist visiting is possible, the need for it is rare.

**Conclusions:** Palliative care input is needed 24 hours a day. This type of service is a good resource for families caring for a loved one at home, empowering them and avoiding unnecessary admissions. This service input in relation to home death merits further work.

Abstract number: FC02.1

**FC02****Pain and symptom management**

Abstract type: Oral

**The Unmet Supportive Care Needs of People with Cancer Pain**

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**Background:** People suffering from cancer pain frequently report the detrimental effect it has upon their lives. Pain is associated with increased levels of distress, reduced quality of life and impaired physical function. From the literature it is unclear whether people with specific types of cancer pain experience unmet supportive care needs.

**Aim:** The aim is to identify the unmet supportive care needs of cancer patients who have pain and explore the factors that contribute to higher levels of unmet needs.

**Methods:** A prospective longitudinal study was used to assess the prevalence of unmet needs of patients with cancer pain in a regional cancer centre. Stratified sampling methods were used to evenly group 162 participants into those with controlled, uncontrolled or breakthrough pain. The participants completed a series of questionnaires, including the Supportive Care Needs Survey- Short Form 34, at two time points, a month apart. 110 participants completed both time points.

**Results:** 80% of the participants reported at least 1 unmet need. The needs in the psychological and the physical daily living domains were the most prevalent. The highest reported needs for help were with concerns about loved ones (50%), lack of energy (49%) and not being able to do the things they used to do (46%), for which the majority of people had a moderate to high need of help. Participants with uncontrolled pain ( $p < 0.000$ ) and breakthrough pain ( $p = 0.022$ ) were more likely to have unmet needs than participants with controlled pain. The prevalence and severity of unmet supportive care needs reduced over time. This was not dependent on an improvement in pain.

**Conclusions:** People with cancer pain require further help from healthcare professionals. Assessment and management of symptoms and specific areas of psychological care may contribute to improvements in pain and subsequently impact on an individual's quality of life.

The Florence Nightingale Foundation sponsored the lead researcher.

Abstract number: FC02.2

Abstract type: Oral

**Revised European Association of Palliative Care Cancer Pain Guidelines: Management of Central Side-effects of Opioids**

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**Background:** The EAPC cancer pain guidelines were last published in 2012 and are currently being updated. The previous guidelines made a weak recommendation that methylphenidate could be used to improve opioid-induced sedation but the threshold between desirable and undesirable effects is narrow. The data also permitted a weak recommendation that in patients with opioid-related neurotoxic effects (delirium, hallucination, myoclonus and hyperalgesia), dose reduction or opioid switching should be

considered.

**Aim:** The aim of this study was to update the previous systematic review on evaluations of management of central side-effects of opioids by conducting a search for papers published between August 2009 and May 2014.

**Methods:** Medline, EMBASE and the Cochrane library were searched using a combination of terms for opioids, cancer, myoclonus, insomnia, hallucinations, fatigue, delirium, hyperalgesia, sedation and confusion.

**Results:** The initial search strategy identified 35 papers. A review of the references from one of these papers identified one further report that was potentially relevant. Therefore, 36 papers were considered in further detail. From these, 24 articles were rejected as falling outside of the selection criteria after screening citations. Thus 12 articles were retrieved for further scrutiny, of which two fulfilled the inclusion criteria. One paper reported the use of lidocaine and ketamine intravenous infusions to treat opioid induced hyperalgesia in 8 cancer patients. The other paper was a prospective study to determine the reversibility of delirium in hospitalised cancer patients using standardised treatment with anti-psychotics and management of the underlying condition. Neither paper contained evidence to support a change in the recommendations of the 2012 EAPC guidelines.

**Conclusion:** The updated systematic review did not identify data to support a change in the existing recommendations about the management of opioid induced CNS side-effects.

Abstract number: FC02.3

Abstract type: Oral

**East/West Differences in the Medical Use of Pain Medicines in the EURO Region: Influence of Country Health Factors Related to Palliative Care**

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**Background:** Pain relief is a prevalent need in palliative care and, especially with severe pain, opioids such as morphine can be clinically warranted. However, country healthcare system characteristics may impede medical use of these essential medicines.

**Aims:** For the first time, multivariate modeling determines how various country factors explain the most current opioid use in the EURO region, and how these influences vary between the East/West designation.

**Methods:** The International Narcotics Control Board provided 2012 opioid use data for European countries. Aggregate amounts of five opioids indicated for severe pain were converted to a total morphine equivalence (ME) for each country, adjusted for population – this was the outcome variable. We examined 5 predictor variables:

- 1) Human Development Index (HDI)
- 2) HIV/AIDS deaths
- 3) Cancer deaths
- 4) Palliative care development
- 5) Government health expenditures.

In addition to descriptive analyses, three multivariate regression models were constructed – one each for the EURO region and for the Eastern- and Western-European country groups – to ascertain important parameter differences among the models. Adjusted  $R^2$  values based on all included variables demonstrated explanatory variability as a function of each model. **Results:** Cancer and AIDS death rates and HDI predicted medical opioid use in the EURO region, but integrated palliative care was variable across Eastern countries. The EURO region model was highly explanatory ( $R^2 = 89\%$ ) and conformed largely to the Eastern country model ( $R^2 = 85\%$ ). These models diverged from the Western country model ( $R^2 = 31\%$ ) having no significant parameters.

**Conclusion:** Recent availability of pain medicines and palliative care services differ substantially between Eastern- and Western-European countries, but also depend on other healthcare system features. Some countries are noteworthy as outliers for certain factors.

**Acknowledgment:** LIVESTRONG, Open Society Foundations

Abstract number: FC02.4

Abstract type: Oral

**Interventions for the Management of Malignant Pleural Effusions: A Cochrane Systematic Review with Meta-analysis**

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**Background:** Malignant pleural effusion (MPE) is a common, disabling condition in patients with advanced cancer. MPE results in breathlessness and confers a prognosis of 3–12 months. The optimal treatment strategy is subject to debate and the Cochrane Collaboration requested an updated review.

**Aim:** To synthesise the existing evidence evaluating the effectiveness of interventions for the management of MPE.

**Methods:** A systematic review was conducted with the Cochrane Pain and Palliative and Supportive Care (PaPaS) Review Group, identifying randomised controlled trials (RCTs) evaluating interventions for adults with symptomatic MPE from three databases in May 2014. There were no restrictions on years searched. The primary outcome was the efficacy of pleurodesis and secondary outcomes included adverse effects, breathlessness, quality of life, mortality, costs and duration of hospital stay. Two investigators assessed study eligibility. Data extraction was performed by two independent assessors, who also assessed risk of bias. Discrepancies were resolved by consensus.

**Results:** 1757 records were identified, 57 of which met the eligibility criteria. Interventions included talc slurry, talc poudrage, bleomycin, tetracycline, C parvum and doxycycline. Direct comparison, using random effects meta-analysis, showed talc poudrage to be superior at pleurodesis than other methods (OR=0.27 [95%CI 0.11 to 0.67],  $P = .62$ ) based on 9 studies. All analyses highlighted substantial heterogeneity. Only three studies were double blinded and all were high risk of bias for at least one risk of bias domain.

**Conclusion:** Direct comparison of talc poudrage with the other agents suggests it may be the best pleurodesis agent. Meta-regression to explore the high degree of heterogeneity will be complete by January 2015 to clarify findings.

Abstract number: FC02.5

Abstract type: Oral

**How Do Patients Experience Opioid Toxicity?***Isherwood R.J.<sup>1</sup>, Haraldsdottir E.<sup>1</sup>, Colvin L.<sup>2</sup>, Fallon M.<sup>3</sup>*<sup>1</sup>Strathcarron Hospice, Denny, United Kingdom, <sup>2</sup>University of Edinburgh, Department of Anaesthesia and Pain Medicine, Edinburgh, United Kingdom, <sup>3</sup>University of Edinburgh, Edinburgh Cancer Centre, Edinburgh, United Kingdom  
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**Background:** It is well-recognised that patients who are on opioids will experience side effects and that these side effects may limit titration of the opioid. Some patients will experience opioid toxicity and, although this usually resolves with dose reduction of the opioid or an opioid switch, the experience can be significant for both the patient and family.

**Aim:** The aim of this study was to describe the patient experience of opioid toxicity.

**Methods:** Seventeen patients with cancer who were prescribed opioids and who had previously been opioid toxic were recruited. Interviews were recorded and transcribed. Quantitative description was used in order to stay true to the descriptions given by the patients. Saturation was reached after 17 interviews. Data was analysed and themes extracted. Analysis was confirmed by a second researcher.

**Results:** Several themes of interest emerged from the data. The patients described significant impact on themselves and were aware of an increased burden of care for their families. Patients modified their behaviour in order to maintain safety. This was particularly important to those with myoclonus. Those who were cognitively impaired during the episode described memory loss and mental slowing. They developed coping strategies to manage the cognitive impairment. Patients felt stigmatised by the cognitive impairment. Several of the patients reported a heightened pain sensitivity which resolved when opioid doses were reduced, along with the other symptoms of toxicity. Patients felt clothes or bedding painful. Others described pins and needles. Patients were also clear that the original cancer pain was not resolving.

**Conclusion:** This study is the first description of the patient experience of opioid toxicity. The impact of the symptoms on the patients is clear. Patients develop coping strategies. The findings of the altered pain experience are new and suggest opioid-induced hyperalgesia is part of the spectrum of opioid toxicity.

Abstract number: FC02.6

Abstract type: Oral

**Economic Evaluation of the Randomised, Double-blind, Placebo-controlled Study of Subcutaneous Ketamine in the Management of Chronic Cancer Pain***McCaffrey N.<sup>1,2</sup>, Flint T.<sup>3</sup>, Kaambwa B.<sup>2</sup>, Fazekas B.<sup>1</sup>, Currow D.<sup>1</sup>, Hardy J.<sup>4</sup>, Agar M.<sup>5,6</sup>, Eckermann S.<sup>7</sup>*<sup>1</sup>Flinders University, PaCCSC, Palliative & Supportive Services, Adelaide, Australia, <sup>2</sup>Flinders University, Flinders Health Economics Group, Adelaide, Australia, <sup>3</sup>York University, York, United Kingdom, <sup>4</sup>Mater Health Services, Brisbane, Australia, <sup>5</sup>Braeside Hospital, HammondCare, Sydney, Australia, <sup>6</sup>South West Sydney Local Health District, Sydney, Australia, <sup>7</sup>Australian Health Services Research Institute, University of Wollongong, Wollongong, Australia  
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**Background:** Ketamine is widely used to treat cancer-related pain and until recently evidence to support its use in this setting was weak. An economic evaluation has never been undertaken in this context.

**Aims:** To evaluate the incremental resource use, cost and consequences of ketamine treatment versus placebo when used in conjunction with opioids and standard adjuvant therapy in the management of chronic, uncontrolled pain in advanced cancer patients.

**Methods:** A within trial cost-effectiveness analysis of the Australian Palliative Care Clinical Studies Collaborative randomised, double-blind, placebo-controlled trial of ketamine was conducted from a health care provider perspective. Censored adjusted mean costs (AUS \$) and effectiveness were calculated from participant-level data (ketamine n=93, placebo n=92) over the five-day treatment period including: positive response; toxicity; quality of life (QOL); ketamine costs; medication usage and inpatient stays. Missing data were estimated with multiple imputation methods and bootstrapping was applied to assess multivariate uncertainty.

**Results:** Positive response rates were similar between ketamine (31%) and placebo (27%). Mean changes in QOL scores from baseline measured with the FACIT-Pal (total score 184) were small and in favour of placebo (ketamine -1.9 (-5.4, 1.4), placebo 4.7 (2.0, 7.5)).

Estimated total mean costs were approximately \$800 higher per ketamine participant (\$8,965) compared with placebo (\$8,193). When incremental costs and effects (QOL) were jointly considered, ketamine was dominated by placebo, i.e. was more costly and less effective. There was almost no chance of ketamine being cost-effective versus placebo when the decision-maker threshold value was \$100,000 for one unit gain in QOL.

**Conclusion:** The findings suggest subcutaneous ketamine in conjunction with opioids and standard adjuvant therapy is neither an effective nor cost-effective treatment for refractory pain in advanced cancer patients.

**FC03****Assessment and measurement tools**

Abstract number: FC03.1

Abstract type: Oral

**Prognosis Prediction by Palliative Prognostic Index (PPI): Multi-centre Prospective Study-2 with Two Calculations of PPI in UK Hospice Patients***Subramaniam S.<sup>1</sup>, Dand P.<sup>2</sup>, Ridout M.<sup>3</sup>, Bright R.<sup>4</sup>, Miller S.J.<sup>5</sup>, Armour K.<sup>6</sup>, Cawley D.<sup>7</sup>, Valli P.<sup>8</sup>, Wilcocks T.<sup>1</sup>, Oliver D.<sup>9</sup>, Parker G.<sup>10</sup>, O'Neil B.<sup>11</sup>*<sup>1</sup>EllenorLions Hospice, Palliative Medicine, Gravesend, United Kingdom, <sup>2</sup>Pilgrims Hospice, Palliative Medicine, Canterbury, United Kingdom, <sup>3</sup>University of Kent, Statistics, Canterbury, United Kingdom, <sup>4</sup>Pilgrims Hospice, Margate, United Kingdom, <sup>5</sup>St. Joseph's Hospice, London, United Kingdom, <sup>6</sup>Marie Curie Hospice West Midlands, Solihull, United Kingdom, <sup>7</sup>Pilgrims Hospice, Palliative Medicine, Ashford, United Kingdom, <sup>8</sup>Heart of Kent Hospice, Maidstone, United Kingdom, <sup>9</sup>Wisdom Hospice, Rochester, United Kingdom, <sup>10</sup>Hospice in the Weald, Pembury, United Kingdom, <sup>11</sup>Greenwich and Bexley Cottage Hospice, London, United Kingdom

**Background:** Predicting prognosis accurately would help patients and clinicians to make informed decisions about treatment and referral to appropriate services. But user-friendly tools are lacking in clinical practice. The Palliative Prognostic Index (PPI), based on simple clinical indicators, has shown promise in several studies.

**Aims:** Following a previous multicentre study in the UK, the current prospective study involved 10 centres, to check centre-to-centre variability, and included a second assessment of PPI score 3–5 days after admission to investigate whether incorporating changes in PPI lead to improve predictions.

**Methods:** PPI score was calculated on admission to inpatient hospice, and again 3–5 days later. Kaplan-Meier curves were constructed and predicted survival based on PPI was compared to actual survival, using standard measures.

**Results:** Initial PPI (PPI\_1) was recorded for 1164 patients. Median survival for patients with PPI\_1 score ≤ 4, 4–6 and > 6 was 38, 17 and 5 days, but there was significant variation between centres. A second PPI value (PPI\_2) was recorded for 962 patients. Most of the remaining patients had high PPI\_1 and died before the second assessment. PPI\_2 was a more reliable predictor of survival than PPI\_1. Based on PPI\_2, the sensitivity, specificity, positive predictive value and negative predictive value for prediction for < 21 days were 64%, 85%, 84%, 65% and for ≥ 42 days were 64%, 77%, 53%, 84%. Again, there was considerable centre-to-centre variability. Kaplan-Meier and ROC curves constructed (Survival < 21 days: PPI1: 0.734; PPI2: 0.820. Survival ≥ 42 days: PPI1: 0.723; PPI2: 0.795). Further analysis of the effect of changes of score and comparison with recent studies from Taiwan and Japan showed similar results in many aspects. Possible causes of variability of results between centres are discussed.

**Conclusion:** PPI score is more accurate if calculated twice and the rate of change of PPI is useful.

Abstract number: FC03.2

Abstract type: Oral

**Validation of Three Different French Forms of ESAS***Pautex S.<sup>1</sup>, Herrmann F.<sup>2</sup>, Beauverd M.<sup>3</sup>, Bernard M.<sup>3</sup>, Cantin B.<sup>4</sup>, Pralong J.<sup>5</sup>, Thollet C.<sup>6</sup>, Bollondy C.<sup>7</sup>, Ducloux D.<sup>8</sup>, Delaloye S.<sup>9</sup>, Wayne-Bossert P.<sup>8</sup>, Escher M.<sup>9</sup>*<sup>1</sup>Community Palliative Care Unit, Division of Primary Care, Carouge, Switzerland, <sup>2</sup>Division of Geriatrics, Geriatrics, Internal Medicine and Rehabilitation, Geneva, Switzerland, <sup>3</sup>Palliative Care, Lausanne, Switzerland, <sup>4</sup>Palliative Care, Fribourg, Switzerland, <sup>5</sup>Palliative Care, Blonay, Switzerland, <sup>6</sup>Palliative Care, Sallanches, France, <sup>7</sup>Direction des Soins, Geneva, Switzerland, <sup>8</sup>Palliative Care, Geneva, Switzerland, <sup>9</sup>Pharmacology and Toxicology, Geneva, Switzerland

**Background:** The Edmonton Symptom Assessment System (ESAS) is a brief, widely adopted, multidimensional questionnaire to evaluate patient-reported symptoms. No validated French version is available.

**Aims:** To develop a French version of the ESAS (F-ESAS), to perform a psychometric analysis in French speaking patients and to define what form (visual [VI], verbal [VE] or numerical [NU]) is more adapted.

**Methods:** In a first pilot study with patients (n=20) and health professionals (n=20) the most adapted terms in French (F-ESAS) were selected and an adapted explanation text was created. In a prospective multicentric study, palliative care patients completed the three forms of F-ESAS (F-ESAS-VI, -VE, -NU) and the Hospital Anxiety and Depression Scale (HADS). Amount of food eaten on the plates was measured. All patients had a test-retest evaluation during the same half-day. Standardised distraction material was used between each scale.

**Results:** 142 patients were included (mean age [±SD]: 68 ± 13; 82 F; 61 M; 126 patients with cancer). Test-retest reliability was high for all 3 F-ESAS and the correlation between these scales was nearly perfect (Spearman rs=0.71-0.92; p<0.05. F-ESAS-VI, -VE and -NU performed similarly and were equally reliable, although there was a trend towards poorer lower reliability for F-ESAS-VI. Correlation between respective F-ESAS depression and anxiety and HADS depression and anxiety were positive (Spearman rs=0.41-0.46 for depression; Spearman rs=0.53-0.57 for anxiety; p<0.05). Correlation between respective F-ESAS appetite and amount of food eaten was positive (rs=0.32-0.43; p<0.05). Respectively 66 (46%), 45 (31%) and 22 (14%) preferred to assess their symptoms with F-ESAS-VE, F-ESAS-NU and ESAS-VI.

**Conclusion / Discussion:** The F-ESAS is a valid and reliable tool for measuring multidimensional symptoms in French speaking patients with an advance disease. The F-ESAS-VE is the most reliable scale, the preferred scale and should be promoted.



**Abstract number:** FC03.3  
**Abstract type:** Oral

## It's a Family Affair: A Genogram Family Tree to Nurture Psychosocial Assessment

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**Background:** A genogram, a three generation family tree, is widely promoted for gathering, recording and displaying family information. Specialist palliative care multi-disciplinary notes meet local, regional and national standards and WHO recommendations of understanding family concerns alongside those of patients.

**Aims:** To increase use of genograms within specialist palliative care nurse (PCNS) clinical assessment, to promote quality, evidence-based nursing care that meets standards.

**Method:** Suggestions on current use of the tool and support required, were sought from 12 PCNSs using questionnaires. A baseline clinical audit of 50 sets of PCNS records & genograms was undertaken against four local standards. Gaps in current practice were identified and intervention applied to advance quality and reduce the theory-practice gap. Re-audit examined the impact of the interventions.

**Results:** 36% completed pre-intervention genograms were documented in clinical records compared to 56% four months post-intervention. All displayed three generations. Results verified that, without a genogram assessment, no patients had three generations of family record in any other template in the electronic documentation system. Overall questionnaire results showed improvement in PCNS skills, knowledge and confidence in all areas.

**Conclusions:** Results demonstrate positive impact of the well received and evaluated project on PCNS clinical practice. Despite a small scale project to support advancing clinical practice, the implication was much wider than anticipated. Genograms have been embedded into the individualised care plan for those thought likely to be dying, and are used by staff of all disciplines across all settings. Action is in place to roll the project out Trust-wide to support these newly developed plans for care. As palliative care is a highly emotive area of practice, with only one chance to get it right, interventions for psycho-social support need to be effective and appropriate.

**Abstract number:** FC03.4  
**Abstract type:** Oral

## Two New Versions of the McGill Quality of Life Questionnaire (MQOL)

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**Background:** The McGill Quality of Life Questionnaire (MQOL) has been widely used to measure the quality of life (QOL) of people with life-threatening illness. Experience with it suggests that minor changes are warranted. Furthermore, although MQOL measures physical, psychological, existential, and support domains, qualitative studies suggest that other domains are also important to consider.

**Aims:**

1. To create a MQOL-Revised (MQOL-R) that measures the same domains as the original while improving MQOL's psychometric properties.
2. To develop a comprehensive version of MQOL (MQOL-C) based on MQOL-R plus other QOL domains.

**Methods:** Data from 5 samples of people with life-threatening illnesses in Canadian healthcare settings were used (n=1178) and compared to data from 3 studies used for the original MQOL validation (n=497). New or revised items that were not included in all samples were imputed using multiple imputation. Confirmatory factor analyses (CFA) and regression analyses of the Global QOL item were conducted to comparatively evaluate modifications of the original MQOL.

**Results:** *Aim 1:* CFA of the MQOL-R with 4 correlated factors resulted in good model fit in the pooled sample of new data (RMSEA=0.041; CFI=0.958). MQOL-R consists of 14 items measuring physical, psychological, existential, and relational wellbeing with internal consistency reliability estimates of 0.66, 0.85, 0.77, and .87, respectively.

*Aim 2:* The domains of cognitive functioning and health care, and two items on the feeling of being a burden and the appraisal of physical surroundings were added to MQOL-R. CFA of the MQOL-C with 8 correlated factors resulted in good model fit in the pooled sample of new data (RMSEA=0.033; CFI=0.963). It consists of 20 items with internal consistency reliability estimates ranging from 0.66 to 0.87.

**Conclusion:** MQOL-R can replace MQOL, while MQOL-C can be used when a more comprehensive measurement is desired and patients are able to complete a 20-item tool.

**Abstract number:** FC03.5  
**Abstract type:** Oral

## Use of the Preparedness for Caregiving Scale in Palliative Care – A Rasch Evaluation Study

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**Background:** Feelings of preparedness can influence the caregiving experience and protect against negative consequences for family carers. Valid and reliable methods are needed to

identify those family carers who may be less prepared for the role of supporting a person who needs palliative care.

**Aim:** To evaluate measurement properties of the original English version and a Swedish version of the Preparedness for Caregiving Scale (PCS).

**Methods:** This is a psychometric evaluation study of the original and a Swedish version of the PCS. The sample for the present study (n=674) was taken from four different intervention studies from Australia and Sweden, all focused on improving family carers' feelings of preparedness. For this study, family carers of patients receiving palliative home care were selected and baseline data was used. The measurement properties of the PCS were evaluated using the Rasch model.

**Results:** The PCS has sound measurement properties according to the Rasch model, both the English and Swedish version. No items demonstrate ceiling or floor effects and the number of missing data was low (< 1%). The items in the PCS captured different levels of preparedness except for persons with very high or low levels. The response categories were appropriate and corresponded to the level of preparedness. No significant differential item functioning for age and sex were detected. Three items demonstrated differential item functioning for language but without impact on interpretation of the score. The findings therefore support the use of the scale for invariant measurements between different groups of sex age and language versions. The reliability was high according to the person separation index (>0.90) and Cronbach's alpha (>0.90).

**Conclusions:** The PCS is valid for use among family carers in palliative care. The extensive evaluation supports the use of the scale across different groups of age and sex as well language versions.

**Abstract number:** FC03.6  
**Abstract type:** Oral

## Glasgow Prognostic Score Predicts Prognosis for Cancer Patients in Palliative Settings – A Subanalysis of the Japan-Prognostic Assessment Tools Validation (J-ProVal) Study

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**Background:** Local and systemic inflammation are important components in the pathophysiology of cancer. The Glasgow prognostic score (GPS), which uses C-reactive protein and albumin levels, offers a good predictor of prognosis in cancer patients undergoing anti-tumor therapy. However, the relationship of GPS to prognosis in cancer patients in palliative settings has not been described.

**Aim:** The objective of this study was to investigate the correlation between GPS and survival among cancer patients in palliative settings.

**Methods:** This was a subanalysis of a multicentre prospective cohort study of 16 palliative care units, 19 hospital palliative care teams, and 23 home-based palliative care services in Japan. Patients not receiving anti-tumor therapy were eligible. Clinical features, including patient characteristics, symptoms, prognostic index and nutritional index, were analysed to investigate prognostic factors.

**Results:** A total of 1160 patients were enrolled in this study (41.6% female; mean age, 70.4 years). In multivariate analysis, the predictors were a GPS score of 2 (hazard ratio (HR), 1.36; 95% confidence interval (CI), 1.01-1.87; p=0.046), presence of liver metastasis (HR, 1.21; 95% CI, 1.03-1.41; p=0.017), dyspnea (HR, 1.35; 95% CI, 1.13-1.59; p < 0.001), edema (HR, 1.25; 95% CI, 1.06-1.48; p=0.009), prognostic performance index > 6 (HR, 1.56; 95% CI, 1.27-1.92; p<0.001), neutrophil lymphocyte ratio ≥ 4 (HR, 1.43; 95% CI, 1.17-1.75; p<0.001), and a performance status of 4 (HR, 1.54; 95% CI, 1.22-1.95; p<0.001). Median survival time with GPS scores 0, 1 and 2 were 58, 43 and 21 days, respectively (p<0.001).

**Conclusion:** The present results indicate that GPS offers a good predictor for cancer patients in palliative settings.

## FC04 Children and international developments

**Abstract number:** FC04.1  
**Abstract type:** Oral

## The Children Experience of Living with a Parent with Amyotrophic Lateral Sclerosis, MAY Emmanuelle, SUC Agnès, TIMSIT Patricia, CINTAS Pascal. (Toulouse, France)

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**Background and aim:** Amyotrophic lateral sclerosis (ALS) is a neurodegenerative disease of unknown origin which affects motor neurons. The only existing treatment aims to slow down the progressive rate of physical impairment. It's currently incurable and the support given falls within the palliative care process.

In our experience, a lot of families met expressed relational difficulties which led us to explore the children's psychological state. Moreover, the parents asked the care team how to announce the disease to their children, to talk about death, disease evolution and the handicap itself.

**Methods:** First, a survey was conducted with the affected families, in order to assess the psychological state of both children and parents. The surveys inclusion criteria were parents

with minor children and/or parents who questioned the team about families' problems. 23 patients were selected and 11 responded to the survey. The 28 children were 45 to 4 years old, average of 16.8 years old, 22 were less than 18 years old. Secondly, we organised preliminary interviews with families, in order to evaluate their needs. **Results:** The first part of the study shows that parents want to convey a positive message to their children and to explain to them the incurability of the disease. They express their difficulties during the announcement. Children asked questions about the disease's aetiology, the transmission, the cure and of mortality. Behavioural changes were observed: children were more supportive, but also more anxious. These results seem to be confirmed by the second part of the study when meeting other families in which children displayed sleep disorders, concentration problems and regular weeping. **Conclusion:** This study has highlighted the presence of psychological consequences for children with ALS parents. The variability of behaviour and reaction, and the difference depending on the age, shows up the necessity to propose various therapeutically respond.

**Abstract number:** FC04.2

**Abstract type:** Oral

#### Advance Care Planning in Children and Adolescents with Life-limiting Diseases: The View of Parents and Professionals

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**Background:** Advance care planning (ACP) was developed to maximise quality of life and ensure autonomy for patients with severe diseases. While ACP has been scientifically validated in adult care, there is little research on ACP for severely ill children/adolescents. Adult concepts need to be adapted to the medical, psychosocial and legal particularities of the pediatric setting.

**Aims:** The aim of this study was to assess the view of multiprofessional care providers and parents with regard to ACP.

**Methods:** We conducted semi-structured interviews with professional experts (n=17) in the care of severely ill children/adolescents as well as bereaved parents (n=10). Participants were selected by maximum variation sampling. Varied characteristics were: professional group/discipline, care setting, child's diagnosis and age, and parent gender. The interviews were analysed using qualitative content analysis.

**Results:** Both professionals and parents consider ACP as useful. Common important elements are: a continuous case manager/ ACP facilitator, full information giving, emergency planning and planning of everyday life. Important aspects for professionals are: increased confidence and decreased personal responsibility through written advance directives. Yet, uncertainties about the validity of ACP documents cause major problems in practice. For different reasons, both medical and psychosocial professionals are worried about making wrong decisions based on a child's advance directive and refuse to take over responsibility. Important aspects for parents are: information, psychological relief and security through repeated discussions. Major barriers are: uncertain prognoses, unclear responsibilities, professionals' and parents' reluctance to discuss end-of-life issues.

**Conclusion:** There is a clear need for ACP in pediatrics. However, professionals' and parents' views differ, and significant barriers exist. These results may inform the development of future pediatric ACP programs.

**Abstract number:** FC04.3

**Abstract type:** Oral

#### End-of-Life Care at Home: Qualitative Evaluation from the Families Attended by the Pediatric Palliative Care Team in the Balearic Islands

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**Introduction:** Pediatric palliative care teams go along with the family and the children during the process of a life limiting or life threatening disease, especially in the end of life when the presence of the team is very important for the symptom and to attend the emotional and spiritual needs of the family and the dying child.

Our team is formed by a pediatrician, a nurse and a psychologist and gives home care when the family and the child want to stay at home. We accompany them and give care until the children dies.

**Aim:** This study aimed to describe how many children died at home in our unit and to explore the satisfaction of the families that preferred home as the place of death for their children being accompanied by the pediatric palliative care team.

**Methods:** A qualitative research design including individual interviews was used to obtain information about the satisfaction and the feelings of the parents whose children died at home during this year.

**Results:** The PPC team attended in person 4 of the 5 home deaths and the other one by telephone because they had returned to their country of origin. 100% of the parents interviewed that spent end-of-life at home were satisfied by the preference of the place of death and would take the same decision again provided they had 24/7 support from a PPC team. All of them felt well supported by our PPC team and were very grateful.

**Conclusions:** Qualitative findings from this study suggest that most of the families that where attended by the PPC unit preferred home as place of death because they have the support from a PPC team. Health policies should implement PPC teams that attend 24/7 for giving end-of-life care at home and support the dying child and their families. 8 children attended by PPC unit died from January to September 2014. 5 died at home and 3 at the pediatric intensive care unit.

**Abstract number:** FC04.4

**Abstract type:** Oral

#### Understanding the End of Life Clinical Problems of Younger Adults and its Impact on their Parents, Siblings and Health Professionals within the Context of Life Transitions to Enhance their Wellbeing

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**Background:** There has been very little research examining the issues of young adults with life limiting illnesses; existing research often fails to acknowledge that young adults may have needs and issues that are distinct and different from other younger children.

**Aim:** This study aimed to examine the life issues of young adults with life limiting conditions known to a children's hospice association in Scotland.

**Methods:** Longitudinal case study approach, clinical case note reviews and semi-structured interviews, conducted at 2 monthly intervals across a 6 month period between April and Oct 2014.

**Findings:** 33 participants took part: 12 young adults (17 and 23 years). Professionals (n=11) and family members (n=10) were nominated by the young adults. A total of 58 interviews were conducted.

**Results:** *Themes: Dependence dichotomy:* physical and health restrictions created an often unwanted dependence, but equally independence created its own tensions in terms of preparedness, confidence and socialisation skills to engage with the wider community, generating challenges for professionals.

*In it together:* centripetal forces brought families/carers together to cope with the situation; 'centrifugal' forces were not always able to be re-established within the family, resulting in family/individual sacrifices, even with support from professionals.

*Biographical uncertainty:* young adults and families had been living with uncertainty, often for many years, with professionals not always able to supply answers; impacting on lack of focus and direction for the young adults as well as loss and grief reactions for family members.

*Conserving integrity:* young adults, families and professionals acted to preserve the integrity of the young adults by supporting social, personal and structural elements in their lives, within the context of living with the life limiting illness. The findings will help inform local and national policy in children's hospices in Scotland.

**Abstract number:** FC04.5

**Abstract type:** Oral

#### The Irish Childhood Bereavement Care Pyramid: A Guide to Support for Bereaved Children and Young People

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**Aim:** In the absence of a national approach to childhood bereavement care in Ireland, the Irish Childhood Bereavement Network (ICBN) sought to design a childhood bereavement framework to guide professionals and concerned adults in identifying and responding to the needs of children and young people who have experienced a loss.

**Design, methods and approach taken:** An expert group working in the area of childhood bereavement was convened to review the adult and child bereavement literature and pertinent local and international policies, in order to establish existing models of bereavement care and core dimensions of best practice. From this review and building on practice experience, a framework was created and piloted with medical, social work, educational professionals and parents.

**Results:** Three key components of childhood bereavement were identified. They are: the needs of a bereaved child or young person, the appropriate supports and services that are required and the competencies needed to deliver an appropriate response. Further, each component was described relative to a four level tiered model reflecting increased complexity. The framework is placed within the context of time, the child or young person's developmental stage and family context. These aspects were mapped into a three dimensional 'Childhood Bereavement Care Pyramid'. Those involved in the piloting of the pyramid found the model to be a concise and accessible visual guide in an area that families and practitioners find most complex.

**Conclusions:** For the first time, a set of complex information was brought together in a user friendly way. The pyramid developed a national pathway to guide families and practitioners to appropriate support and services for vulnerable children and young people who are bereaved. Further, the competencies identified allows for the development of appropriate training curricula needed at each level.

**Abstract number:** FC04.6

**Abstract type:** Oral

#### The Development of European Consensus Norms for Palliative Care of People with Intellectual Disabilities: An EAPC White Paper

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**Background:** There is growing evidence that people with intellectual disabilities (ID) lack

equal access to palliative care services. The EAPC approved a 2-year Task Force on palliative care for people with ID (2012-2014).

**Aims:** To develop consensus norms for palliative care of people with ID in Europe.

**Methods:** Draft norms were agreed with a steering group of 14 experts in nine countries. Delphi methods were used to assess cross-country agreement with these draft norms, via an electronic survey. They were also invited to provide additional comments to each norm. The norms were accepted if there was sufficient agreement among all respondents (80% or more).

**Results:** The draft norms consisted of 52 items in 13 categories: equity of access, communication, recognising the need for palliative care, assessment of total needs, symptom management, end-of-life decision making, involving those that matter, collaboration, support for families and carers, preparing for death, bereavement support, education/training, and developing/managing services. Eighty usable survey responses were received from 17 European countries. There was strong consensus among survey respondents, with none of the items scoring less than 86% agreement. Following the free text comments, several suggested changes in wording were agreed with the steering group. The final norms are awaiting approval from the EAPC Board of Directors. Challenges included the disparity in service provision for people with ID across Europe, as well as disparity in available palliative care services.

**Conclusion:** The aspirational norms described in this White Paper serve as guidelines for best practice that are accepted across Europe. Further study is needed to assess the barriers and enablers to achieving these consensus norms throughout Europe.

**Abstract number:** FC05.1

## FC05

### Spirituality and social work

**Abstract type:** Oral

#### Understanding Cultural Dimensions of Spiritual Care: A Qualitative Study of Spiritual Care Providers in South Africa, Uganda and Denmark

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**Background:** Understanding the nature of spiritual care (SC) in multi-cultural populations was found to be a major research priority in the EAPC SC Task Force survey. As spirituality is expressed via culture and religion, this evidence is needed to inform SC.

**Aim:** To explore the practice of SC in palliative care (PC) cross-culturally.

**Methods:** A secondary analysis was conducted of in-depth qualitative interview data from two studies of SC providers (SCPs) in South Africa, Uganda and Denmark. Semi-structured interviews were conducted in English and Danish with self-identified SCPs in a range of PC settings, recorded and transcribed. Interviews covered personal background, experiences of providing SC, patients' spiritual needs and challenges encountered in SC provision. Comparative thematic analysis explored the nature of patients' spiritual concerns and how different cultural contexts influence SC provision.

**Results:** In South Africa and Uganda, 21 SCPs were interviewed, including pastors, volunteers, social workers and nurses from 4 PC services. All were Christians except for one Zen Buddhist. In Denmark, 14 interviews were conducted with 12 pastors and 2 imams at 11 PC services. Universal spiritual problems faced by patients were described (e.g. loneliness, meaninglessness, anger) and specific problems related to cultural context (in Africa, HIV stigma, conversion, fear of witchcraft; in Denmark, aversion to proselytising). Among SCPs, two main approaches were identified: pastoral care from a religious perspective and care with an existential focus. Both approaches were culture-specific in the way they used language and supported patients' meaning-making.

**Conclusion:** Comparing SC in three different cultural contexts highlights the universal and culturally-specific features of SC, demonstrating ways in which SC is multi-dimensional, individualised to patient and provider, and interrelated with cultural context. This evidence informs SC and SC research internationally.

**Abstract number:** FC05.2

**Abstract type:** Oral

#### Qualitative Investigation of Understandings of Spiritual Wellbeing (SWB) Collected during Cross-cultural Validation of An EORTC Measure of SWB

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**Background and aim:** In 2002 the EORTC Quality of Life Group began international

development of a spiritual wellbeing (SWB) measure for palliative cancer patients. Final validation field-testing ran in 2012-13. The underpinning theory for the study was of SWB as subjective and individual, but with three broad domains: relationship with self and others, existential, and religious. One aim of the validation study was to explore qualitatively participants' own understandings of SWB.

**Methods:** Participants' socio-demographic and clinical data was collected. All participants completed the provisional measure, then took part in a structured debriefing interview. The last two items of the measure asked participants to state if they had SWB on a 4-point scale (not at all-very much), and then rate their SWB on a 1-7 Likert scale. However, no definition of SWB was provided. The subsequent interviews *inter alia* asked participants what SWB meant to them. If needed, study collaborators translated responses into English. A qualitative thematic analysis was then conducted.

**Results:** 458 patients in 14 countries on 4 continents took part: 188 Christian, 50 Muslim, 23 Buddhist, 158 no religion. Most could define SWB, some with just one word or concept, others using more than one. Several broad themes were identified, largely relating to the hypothesised domains and/or specific items, e.g. living well, good relationship with God, good relationships with others, being at peace with self and/or others. All themes emerged across all participants' responses, but most participants with active religious faith (and some without) defined SWB in relation to God; some just this, others together with other themes.

**Conclusions:** Each study participant had a particular understanding of SWB, but common themes emerged from all participants' responses, which mapped onto the hypothesised domains. The understandings of SWB of those participants with religious faith mostly, although not universally, included God.

**Abstract number:** FC05.3

**Abstract type:** Oral

#### From Insights to Outlooks – An International Study Week on Volunteers in Hospice and Palliative Care

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**Background and aims:** As demographic and epidemiological issues have an impact on palliative care needs of populations, societal changes and the spectrum of diseases addressed by palliative care may require a revision of the role of volunteers. In a multiprofessional and interdisciplinary discourse with international experts and scholars we wanted to discuss sustainable concepts of voluntary work (VW) for the future and identify topics for research.

**Design:** An interdisciplinary study week on ethical, social and legal aspects of the modern life-sciences was funded by the German Federal Ministry of Education and Research (BMBF). Submitted abstracts of young scholars were reviewed by a scientific advisory board and thematically categorised for discussion into:

- a) motivation, attitude of volunteers
- b) challenges in ageing societies
- c) society and volunteers
- d) bereavement and spirituality.

Eight international experts were invited to present and lead workshops.

**Results:** Thirteen applicants (D, A, PL, UA, EAU) were selected. The interdisciplinary discourse demonstrated the need to focus on at least three fields of interest:

- 1) *Terminology* – what does it mean when we talk about volunteers, VW, professional volunteers, civic engagement?

- 2) *Guidelines* – There seems to be a need for guidance, for example with the definition of standards and guidelines, but how much do standards impede the flexibility that is a core element of VW in hospice and palliative care?

- 3) *Core competencies* – What are the core competencies of volunteers in hospice and palliative care, across settings and healthcare systems? Experts and participants of the study week will work on these topics as part of the work of the EAPC Task Force on Volunteering. Significant outcomes will be published.

**Conclusions:** Research on volunteering, especially in an international context, is sparse. The discourse was very enriching, showed potential lessons to be learned from international and intercultural exchange of experiences and approaches.

**Abstract number:** FC05.4

**Abstract type:** Oral

#### Dancing to a Different Tune: Living and Dying with Cancer, Organ Failure and Physical Frailty

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**Background:** The "danse macabre" has been depicted in Europe since medieval times. Providing good end-of-life care for all patients, whatever form their last dance takes, is a recognised global challenge.

**Aims:** To see if there are typical narratives of living with and dying from advanced illnesses, to provide insights into providing effective care.

**Methods:** A synthesis of data from 8 qualitative longitudinal studies: 3 cancer; 3 organ failure; 1 frailty;

1 with South Asian participants from all 3 trajectories. Patients were interviewed up to 4 times over 18 months. Researchers from each study reviewed the data using a narrative analytic framework. The narratives were initially synthesised by illness trajectory (cancer, organ failure or frailty) then compared across the phases of the illness narrative. The findings were iteratively discussed at analysis workshops.

**Results:** The dataset was 828 in-depth interviews with 156 patients. Cancer narratives had a clear beginning, middle and anticipated end, giving a well-rehearsed account of the illness, with dual themes of hope for recovery alongside fear of dying. People with organ failure struggled to tell their story, being unclear when the illness began, or how one event linked to another. Fewer spoke about death, hoping instead to avoid further deterioration. Many



attributed their poor health to 'old age'. Frail older people's narratives often began with a specific event in combination with ageing to make sense of their situations yet lost salience amidst increasing losses and future fears. Death was only fully anticipated very near the end, and feared less than nursing homes or dementia.

**Conclusions:** Patients from different illness groups give very different accounts. Consequently the cancer-based model of end-of-life care seems poorly suited to the needs of those dying in other ways. Understanding how different patient groups perceive their deteriorating health and approaching death can inform appropriate palliative care.

**Abstract number:** FC05.5  
**Abstract type:** Oral

### Outcomes of an EAPC White Paper on Core Competencies for Palliative Care Social Work in Europe

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**Aims:** An EAPC Social Work Task Force was established in 2009 to consider the diversity of roles of social workers in palliative and end of life care across Europe and make recommendations on the core competencies necessary for high quality practice.

**Methods:** The authors drew on the practice experiences of social workers from across Europe, combined with a scoping of the international literature on social work competencies from Canada and Ireland. Other sources included the International Federation of Social Workers and survey work with palliative care social workers in the United Kingdom.

**Results:** This White Paper explores the place of social work in palliative care from a range of perspectives and against the backdrop of variable service provision in Europe. It examines the historical development of the specialism in relation to some of the challenges presented by an ageing population and shrinking resources across the continent. Ten core competencies for palliative care social work are presented which address:

- Principles
- Assessment
- Decision making
- Care planning
- Advocacy
- Information sharing
- Evaluation
- Interdisciplinary working
- Education and research
- Reflective practice

Each detail the values, attitudes, knowledge and skills required for competent work at this specialist level and provide the first opportunity to consider these in a wider European context.

**Conclusion:** This White Paper will enable all interested parties to engage in a debate that seeks to advance the practice of palliative care social work in Europe. In addition, it will form the basis for the development of new curricula for the on-going education of current practitioners and for those coming into this specialised field in the future. Further, it will be an aid to employers seeking to engage specialist social workers in palliative care.

**Abstract number:** FC05.6  
**Abstract type:** Oral

### Social Work in Palliative Care in Germany - Presence and Main Foci of Activity

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**Background:** Psychosocial care is an integral part of palliative care and social work is one key provider of psychosocial care.

It is still unclear, however, how many social workers are present in this field and what are their main foci of activity in the different palliative care settings.

**Aim:** This study explores how present social workers are in the differing palliative care settings in Germany and what their main foci of activity are.

**Methods:** Directors of all palliative care units, of all hospices and of all hospice services in Germany were asked to fill out a questionnaire about elements of psychosocial care, involved team members, the particular role of social work, as well as key data of the service providers.

**Results:** The response rate ranged from 41% (PCUs) to 52% (hospices) and 40% (hospice services). Social workers were present in 86% of the PCUs, in 48% of the hospices and in 22% of the hospice services. In PCUs, social workers were seen as mainly responsible for psychosocial care. In hospices and in hospice services, nurses respectively hospice volunteers are the main providers. In all three settings, the most frequently named tasks of social work are common aspects of clinical social work (e.g. counselling on social assistance laws). In addition, in PCUs social work is responsible for the assessment of personal and social history, individualised counselling and arranging transfer to other care facilities. In hospices, mediation between patient, family and team, arranging services for bereaved persons and organising voluntary work are further tasks and in hospice services coordination activities and other tasks that do not directly concern patients (e.g. fundraising).

**Conclusion:** Social work is the third professional pillar in palliative care, responsible for a wide range of tasks. Data analysis is still ongoing. At the congress, we will be able to present the results in more detail.

## FC06 Ethics and concepts

**Abstract number:** FC06.1  
**Abstract type:** Oral

### Muslim End of Life Ethics: Patiently Respecting Allah's Plan

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**Background:** In just a few decades Islam has become the second largest religion in most European countries. This evolution constitutes an important challenge to European health care (including palliative care), as this is still deeply influenced by secular-Western and/or Christian approaches.

**Aims:** The exploratory research programme (2002-2014, 3 PhDs) presented here aimed to analyse and compare contemporary international normative muslim end of life ethics and real world end of life views and attitudes of elderly Muslims in Flanders, Belgium.

**Methods:** (1) A systematic review of the available empirical studies on Islam and end of life issues (PubMed; snowball)

(2) A content review of the international Islamic discussion on end of life ethics (key authors; international Muslim organisations; e-fatwas on international Islamic websites)

(3) Semi-structured interviews with elderly Moroccan men (20 interviews), elderly Turkish and Moroccan women (60) and specialists (20). All interviews were transcribed, coded and categorised using Grounded Theory methodology.

**Results:** We found hardly any differences between the guidelines in the international normative sources and the actual attitudes of our respondents. Euthanasia and assisted suicide are strongly rejected; non-treatment decisions and the refusal of treatment are only allowed in exceptional circumstances; pain control does not pose an ethical problem. God controls illness and health, life and death; it is unacceptable to interfere in this divine plan. Patience is the central virtue.

**Discussion:** The attitudes of the generation of Belgian Muslims studied here are deeply influenced by a shared religious framework. Nevertheless, even in these very homogeneous groups a few dissident voices were found. In palliative care it remains essential to start from the ethical and religious views of the unique individual in front of you; not from the views that are typically associated with the community he/she belongs to.

**Abstract number:** FC06.2  
**Abstract type:** Oral

### To Explore the Relationship between the Use of Sedative Drugs and Cessation of Oral Intake in the Terminal Phase of Hospice Inpatients: A Retrospective Case Note Review

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**Background:** Sedative drugs are used to treat agitation in dying patients. The most commonly used drug is midazolam. There is concern that the use of sedative drugs results in shortened survival by reducing patients' ability to maintain nutrition and hydration. However, in the last days of life, patients often have impaired conscious levels and an inability to maintain oral intake as part of the natural dying process.

**Aim:** To establish whether oral intake is related to the use of sedative drugs in the last week of life.

**Methods:**

*Design:* A retrospective case note review of 84 inpatients at a palliative care unit in London.

*Data collection:* The data was obtained from nursing records and medication charts of the last 7 days of life of 84 consecutive inpatients that died from 01/01/2012.

Oral intake was classified:

0 – no intake

1 – mouthfuls/sips

2 – small meals

3 – good appetite

Daily doses of midazolam ( $\geq 5$ mg) were recorded.

*Analysis:* Descriptive statistics were used.

**Results:** 51 patients received midazolam on one or more days (Midazolam Group MG), 33 received no midazolam (Controls CG).

Terminal agitation was the commonest reason for midazolam use.

Number of days before death	7	6	5	4	3	2	1
Mean oral intake for all patients	1.21	1.12	1.12	0.93	0.84	0.66	0.33
Mean oral intake for CG	1.45	1.39	1.42	1.09	1.09	0.85	0.50
Mean oral intake for MG	1.05	1.00	0.92	0.83	0.67	0.54	0.17
Mean dose (mg) of midazolam within MG	1.5	1.6	2.1	4.5	6.0	9.9	18.7
Daily number of pts receiving midazolam	4	5	6	14	19	33	49

[Oral intake and midazolam in the last week of life]

**Conclusions:** Mean oral intake was already markedly reduced 7 days prior to death in all patients and continued to decline progressively over subsequent days whether or not a sedative was used. Patients in the MG had even lower initial oral intake, suggesting that they were more unwell. The number of patients requiring midazolam increased closer to death and most patients (63%) received midazolam for less than three days. Mean doses of midazolam used were low. Study limitations are its retrospective nature and reliance on nursing records.

**Abstract number:** FC06.3  
**Abstract type:** Oral

## How and Why Did Belgium Come to Allow Euthanasia for Minors? A Descriptive and Ethical Analysis

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**Aims:** In early 2014 Belgium controversially amended its euthanasia law, making it legal for minors to request euthanasia if they are judged to have 'capacity for discernment'. This raises various ethical questions, the answers to which are relevant worldwide. The aim of this presentation is

- (1) to briefly sketch how the law came about and
- (2) analyse the most important arguments raised both against and in favour of this amendment.

**Methods:** This study concerns an analysis of the various official written reports of the Belgian Senate and House of Representatives which give first hand insight into how the law came to pass and which issues were raised during this process. From these reports the history of the amendment is sketched and the most raised ethical arguments are identified and analysed using existing international research and literature.

**Results:** Documents show that whether minors should be allowed to request euthanasia has been debated in Belgium since the passing of the initial euthanasia law in 2002. Though controversial, the amendment that was passed is the result of significant compromise as more radical and far-reaching proposals were made. As regards the arguments, the most often voiced arguments in favour of the new amendment are that it would avoid discrimination and would give legal security. Critics most often point to the fact that the law may be unnecessary, contains significant uncertainties, and is inattentive to the fact that minors are often not fully competent to make such big decisions. These arguments will be analysed for their ethical validity.

**Conclusion:** Even within Belgium the 2014 amendment was far from uncontroversial. Debate was fierce and many arguments were voiced both for and against, though a significant number of these are, ethically speaking, invalid. In short, this presentation will give an insight into how Belgium came to pass such a controversial amendment.

**Abstract number:** FC06.4  
**Abstract type:** Oral

## Ethical Decisions in Palliative Care: A Burnout Risk Factor? Results from a Mixed-methods Multicentre Study in Portugal

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**Background:** Ethical decision-making in end-of-life care is perceived as stressful. Making ethical decisions is related to higher levels of burnout among health professionals.

**Aims:** To identify the most common ethical decisions made by Portuguese palliative care teams and understand how the making of such decisions relates to burnout.

**Methods:** Mixed methods study in 9 palliative care teams. Data was collected through: questionnaires of socio-demographic and profession-related variables, and work-related experiences; Maslach Burnout Inventory; interviews; observations. Quantitative data analyses included descriptive, uni and multivariate logistic regressions; qualitative data was analysed inductively with themes/categories emerging from data. Triangulation ensured reliability. A total of 88 professionals (66% response rate) were included, 11 nurses and 9 physicians were interviewed and 240 hours of observations were fulfilled.

**Results:** The most common ethical decisions were caused by communication issues, forgoing treatment and terminal sedation. Although perceived as a burnout risk factor in the speech of the participants, quantitative data showed that making ethical decisions was not significantly associated with burnout. These findings were explained through the analysis of the transcripts of interviews and field-notes: The decision-making process using an interdisciplinary team approach and consulting ethical committees were identified as protective factors against burnout.

**Conclusions:** Making ethical decisions is not associated with burnout among professionals working in Portuguese palliative care teams. This is explained by the ethical deliberation and decision-making process followed by these teams. Promoting palliative care skills among professionals providing end-of-life care in other settings might be useful to diminish burnout related to making ethical end-of-life decisions.

**Acknowledgments:** Fundação Grünenthal and Fundação Merck, Sharp and Dohme.

**Abstract number:** FC06.5  
**Abstract type:** Oral

## Can Saving Money Be Unethical? Managing Conflict of Interest in Advance Care Planning

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**Background:** While advance care planning (ACP) primarily aims at realising patient autonomy during the last phase of life, it may also reduce the costs of care. Given the increasing economic pressure in most health care systems, the sensitive ACP-communication process might be unduly influenced by cost-considerations.

**Aims:** To analyse potential conflicts of interests resulting from the cost implications of ACP programs and discuss corresponding ethical safeguards.

**Approach:** We assessed

- (1) the cost-implications of ACP by a systematic review and
- (2) the resulting conflicts of interest by analytical ethical investigation.

**Results:** Six of seven studies included in the review demonstrated cost reductions through ACP ranging from \$1,041 to \$64,830 per patient, which lets ACP appear an attractive tool for payers and policy makers (despite open questions regarding the direct and also the indirect costs of ACP). This involves, however, a considerable potential for conflicts of interests: incentivised facilitators might undermine the openness of the planning process, or

individuals might feel obliged to opt "autonomously" for less costly care. As a consequence, safeguards for patient autonomy are required: first of all, research must reveal financial gains and losses caused by ACP programs so payers' and policy makers' potential goals become transparent. The primary goal must remain to realise patient autonomy (and high quality care) near the end of life, even if this increases costs of care. Most importantly, quality and thereby openness of the facilitation process must be assured. Furthermore, facilitators should be specifically trained to manage potential conflicts of interest.

**Conclusion:** The potentially conflicting goals of ACP, realising patient autonomy and containing costs, require safeguards to guarantee the openness of the facilitation process.

**Abstract number:** FC06.6  
**Abstract type:** Oral

## A Palliative Approach: A Concept in Need of Clarity

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**Background:** Much of what we understand about the design of healthcare systems to support care of the dying comes from our experiences with caring for dying cancer patients. It is increasingly recognised, however, that in addition to cancer, high quality end of life care should be an integral part of care that is provided for those with other advancing chronic life-limiting conditions. A *palliative approach* has been articulated as one way of conceptualising this care but there is a lack of conceptual clarity regarding its essential characteristics.

**Aims:** To delineate the key characteristics of a palliative approach found in the empiric literature in order to establish conceptual clarity.

**Methods:** We conducted a mixed-methods knowledge synthesis of empiric peer-reviewed literature. Established knowledge synthesis procedures were implemented. Search terms pertaining to "palliative care principles" and "chronic life-limiting conditions" were identified. A comprehensive database search yielded 73 studies. Narrative synthesis methods and thematic analysis were used to identify and conceptualise key characteristics of a palliative approach.

**Results:** Our review revealed a burgeoning body of knowledge. Three overarching themes were conceptualised that characterise a palliative approach:

- (1) Upstream orientation towards the needs of people who have life-limiting illness and their families.
- (2) Adaptation of palliative care knowledge and expertise.
- (3) Operationalisation of a palliative approach through integration into systems and models of care that do not specialise in palliative care.

**Conclusion:** Our findings provide much needed conceptual clarity regarding a palliative approach and its delineation from palliative care. Such clarity is of fundamental importance for the development of knowledge regarding the integration of a palliative approach in the care of people with chronic life-limiting illnesses.

**Funding:** Canadian Institutes of Health Research

## FC07

### Palliative care in non-cancer

**Abstract number:** FC07.1  
**Abstract type:** Oral

## Preferences for End of Life Care and Treatment for Advanced Chronic Obstructive Pulmonary Disease (COPD) Patients: Results from a Discrete Choice Experiment

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**Background:** COPD is a chronic progressive condition with high symptom burden accounting for 26,000 deaths annually in England alone. Little is known about patients' preferences for care and how they change in advanced disease.

**Aims:** To identify patients' preferences for care in advanced COPD, and explore how these preferences change with deterioration in condition.

**Methods:** A discrete choice experiment was developed and included in a postal questionnaire. 305 patients with advanced COPD, recruited from GP practices in Eastern England and South London, participated in a three-wave six-monthly postal survey. In the choice experiment, each respondent considered five different vignettes describing different health states, and for each indicated their preferences for source and place of care should they experience an exacerbation. Both the health states and the care options available were varied within the survey. Twelve different versions of the questionnaire were used, enabling coverage of sixty different care choice contexts.

**Results:** The discrete choice model estimated from this data provides insight into the weight that respondents put on different aspects of care: whether to receive care at home or at hospital; who leads the care decisions in each setting; the support available outside of routine appointments; and the time to access this support. Respondents' demographics, exacerbation history and quality of life are incorporated into the model, revealing that these factors have a statistically significant influence on patients' preferences for both who makes the care decisions and the location where the care is provided.

**Conclusions:** This research provides new evidence enabling appropriate end-of-life care and support of advanced COPD patients living in rural-urban and inner-city regions. It will help health service providers to identify possible service modifications to meet COPD patients' needs.

**Funders:** Marie Curie Cancer Care and NIHR

**Abstract number:** FC07.2  
**Abstract type:** Oral

### **Towards Integration of Palliative Care in Patients with Chronic Heart Failure and Chronic Obstructive Pulmonary Disease: A Systematic Literature Review**

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**Background:** The concept of palliative care (PC) is traced to cancer care, but is also encouraged for patients with chronic disease. Despite the positive impact of PC on the quality of life for patients and their relatives, the implementation of PC in non-cancer healthcare delivery in the EU seems scarcely addressed.

**Aims:** To assess guidelines/pathways for integrated PC in patients with chronic heart failure (CHF) and chronic obstructive pulmonary disease (COPD) in Europe via a systematic literature review.

**Methods:** *Design:* Search results were screened by two reviewers. Eligible studies of adult patients with COPD or CHF published between 1995 and 2013 in English, French, German, Dutch, Hungarian or Spanish were included. Guidelines were ranked using Emanuel's tool for the screening and evaluation of the PC content of the studies, with an entry threshold of 2 out of 11 criteria.

*Data collection:* Nine electronic databases were searched. BMJ Palliat. Support Care, Eur. J. Palliat. Care, J Pain Symptom Manage, J. Palliat. Med and MED PALLIATIVA and references from included studies were hand-searched. Citation tracking was also performed.

*Analysis:* The acquired data were heterogeneous. A narrative synthesis was employed for documenting quantitative and qualitative results.

**Results:** 55 studies were included; 44 guidelines and 11 pathways. 75% focused on a holistic approach, 89% on PC interventions aimed to reduce suffering, 71% on the assessment of the patients' goals of care and advanced care planning, and 69% on the involvement of a PC team. Finally, 45% elaborated on the referral criteria.

**Conclusion:** The importance of employing an integrated approach to PC is acknowledged by the majority of the included studies. Discrepancies concerning the referral criteria hint that the implementation aspects are obscure. Eight studies scored 10/11 in Emanuel's criteria and can serve as examples for the design of PC guidelines/pathways for CHF and COPD.

**Abstract number:** FC07.3  
**Abstract type:** Oral

### **TOPCare: Results from a Mixed Methods RCT Testing a Nurse-led Intervention to Reduce Symptom Burden and Improve Quality of Life for People on ART in Kenya**

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**Background:** Latest guidance means that greater numbers of people will live on treatment, and evidence persists of high burden of physical, psychosocial distress.

**Methods:** A mixed methods trial aimed to reject the null hypothesis that adults on ART receiving a nurse-led person-centred intervention implementing palliative care principles will not improve quality of life (physical and mental) and multidimensional wellbeing (in line with WHO palliative care definition) compared to standard care. Conducted at a Kenyan Mission Hospital public clinic, data were collected at baseline and monthly using locally validated measure. Five quantitative datapoints: GHQ for psychological morbidity, MOS-HIV for mental and physical quality of life, and POS for multidimensional wellbeing, plus qualitative data after trial exit. Intervention patients had appointments with an existing ART clinic nurse trained in palliative care, using a multidimensional assessment protocol and care planning.

**Results:** The trial recruited the fully powered sample size of 120 patients. GLLAMM analysis (to account for clustering of scores) found the following results: the intervention arm showed quantitative improvement for all outcomes. GHQ coefficient -0.50 (95% CI 0.96, -0.03),  $p=0.035$ ; MOS-HIV physical 0.44 (-0.02, 0.91),  $p=0.06$ ; MOS-HIV mental 0.59 (0.12, 1.07),  $p=0.015$ ; POS 0.69 (0.26, 1.12),  $p=0.002$ . Qualitative data revealed key elements of the intervention were being treated with respect, being listened to and having concerns heard. The control group also described value in the research process of regular interviews asking about wellbeing. Both groups articulated need (and resolution) of psychosocial domains of need, specifically perceived stigma.

**Conclusions:** A simple brief training course and assessment/management protocol in palliative care improved outcomes. The core elements of person-centred care and regular assessment can easily be incorporated into routine practice.

**Abstract number:** FC07.4  
**Abstract type:** Oral

### **The Two Minute Walk Test (2MWT) Is a Safer and More Effective Measure of Functional Capacity than the Six Minute Walk Test (6MWT) in Advanced COPD**

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**Background:** The BODE index is routinely used in Specialist Outpatient Clinics (SOC) to predict survival and hospitalisations in COPD. However, performing the 6MWT as part of BODE is challenging in severe airflow limitation. We hypothesise that a 2MWT is as effective as a 6MWT in measuring functional capacity in advanced COPD.

**Aims:** Our primary aim is to compare the 2MWT with the 6MWT by measuring their association with functional capacity as measured by the Modified Barthel Index (MBI). As

secondary objectives, we compare the 2MWT and 6MWT by measuring their association with quality of life (QoL), airflow limitation (FEV<sub>1</sub>), BODE score, dyspnea intensity and exacerbation frequency.

**Method:** Subjects with stage 3 and 4 COPD are recruited at the SOC. 6MWTs were conducted with pulse-oximetry reading at 0, 2, 4 and 6 minutes. Subjects could discontinue if they experienced fatigue or desaturate to  $\leq 90\%$ .

**Results:** Of 104 subjects recruited, 69 (66%) has stage 3 and 35 (34%) has stage 4 COPD. 97.1% could complete the 2MWT, whereas only 47.1% could walk the full 6 minutes, with 40.4% of subjects desaturating to  $\leq 90\%$  by the end of 2 minutes.

The 2MWT has stronger correlation to MBI than the 6MWT ( $r=0.61$  vs  $0.37$ ;  $p<0.001$ ). Low 2MWT distances strongly associate with heightened perception of dyspnea, and poor prognostic scores (BODE). It moderately correlates with low FEV<sub>1</sub>, and disease specific QoL (all  $p\leq 0.001$ ). The strength of these correlations with the 2MWT exceeded those with the 6MWT. Using linear regression, multivariate analysis confirms the 2MWT as a predictor of MBI (Beta 0.37;  $p=0.001$ ) independent of other variables identified through univariate analysis.

**Conclusion:** The 2MWT is a safe and effective measure of exercise capacity. High correlation coefficients between 2MWT, 6MWT and BODE strongly suggests its potential to replace the 6MWT in advanced COPD. By itself, it shows good potential as a screening tool to discern frailer COPD patients for early palliative intervention.

**Abstract number:** FC07.5  
**Abstract type:** Oral

### **Understanding the Care Pathway of Patients with Cirrhosis in the Last Year of Life**

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**Background:** Liver disease is a growing global public health problem and the 5<sup>th</sup> largest cause of death in the UK. Health policy for this patient group primarily centres on prevention, paying minimal attention to improving end of life care for those affected.

**Aims:** To follow patients with cirrhosis in the last year of life, plotting healthcare use and identifying barriers to good end of life care.

**Methods:** Retrospective review of purposively selected case notes (30 cirrhotic patients) referred to a tertiary London liver unit. Pathways of care were modelled, by combining clinical data and service utilisation information extracted from medical notes, and qualitative focus groups/ interviews with 20 liver health professionals, about barriers to good end of life care.

**Results:** During the last 12 months of life, medical crises often precipitated unplanned emergency admissions to hospital. Patients experienced high symptom burden and were repeatedly treated intensively to aid recovery. Although clinicians recognised that limited treatments and services exist to address patients' problems, many continued to treat patients actively.

Opportunities to initiate palliative care were documented but not always acted upon. Discussions were rarely held with patients about their future wishes; care planning conversations occurred late in the patient trajectory and were more likely to occur with the patient's family. Specialist palliative care referral occurred within the last few days of life.

**Conclusions:** Clinicians have difficulties identifying when to initiate end of life care for patients with cirrhosis, when prognosis is uncertain and active treatment may afford a degree of short term recovery. Earlier integration of palliative care would facilitate care planning discussions and better inform patients and families of the choices available, in the knowledge they may be entering the dying phase.

**Abstract number:** FC07.6  
**Abstract type:** Oral

### **The Challenge of Pervasive Uncertainty in Advanced Liver Disease**

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**Background:** The number of patients dying with advanced liver disease is rising rapidly, yet little is known about the experiences and support needs of these patients and their carers. Palliative care services are increasingly recognising the needs of non-cancer patients, but liver disease remains relatively neglected.

**Aims:** To explore the dynamic physical, psychosocial, existential and information needs of patients and their lay and professional carers, and to review their use of health, social and voluntary services.

**Methods:** Qualitative, multi-perspective, serial in-depth interviews. Patients with different types of liver disease were recruited in hospital. They and their lay carers were interviewed up to 3 times over one year. Case-linked professionals were interviewed once. Interviews were recorded, transcribed and analysed using grounded theory techniques and NVivo 9.

**Results:** 15 patients and their carers were recruited and 64 interviews conducted. Uncertainty emerged as the central factor dominating experiences across all domains, at all stages of the illness, and for all participants: patients, lay carers and professionals. This uncertainty related to the nature of the illness, the unpredictability of the disease pathway and prognosis, poor communication and information-sharing, and complexities of care. Coping strategies sought to manage, rather than reduce, uncertainty. Pervasive uncertainty makes care planning especially important, yet impeded this very process.

**Conclusion:** This is the first serial interview study of people with advanced liver disease. It locates uncertainty at the heart of the experiences of patients, lay and professional carers. Given its critical impact on the patient experience, professionals must address this uncertainty while recognising its role in patients' coping. More needs to be done to ensure that people with advanced liver disease receive appropriate and equitable supportive and palliative care. Study funded by the ESRC.



## FC08

## Development and organisation of services

Abstract number: FC08.1

Abstract type: Oral

**A Shared Electronic Record for Personalised End-of-Life Care: Factors Associated with Achieving Preferred Place of Death***Yau W.S.<sup>1</sup>, Droney J.<sup>2</sup>, Howard D.<sup>3</sup>, Shaw M.<sup>3</sup>, Riley J.<sup>4</sup>*

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**Background:** Achieving a patient's preferred place of death (PPD) is a key quality indicator for end-of-life care. We have established an electronic care record to document patient care wishes and personalised care plans. The care plan can be accessed electronically by all legitimate providers of urgent care including ambulance staff, general practitioners, hospitals, nursing and care homes, hospices and community nursing teams.

**Aims:** To measure the proportion of patients included in this electronic care system who have achieved their PPD and to identify any factors that may be associated with achieving PPD or not.

**Methods:** A retrospective data analysis of patients who had an electronic care record created between April 2013 and March 2014. Statistical analyses were performed using SPSS. Descriptive statistics was used.

**Results:** There were 1379 patients included in the study. 80.9% of patients achieved their PPD. Most of the patients' PPD was usual place of residence (82.6%); home (62.1%) and care home (20.5%). Older age ( $p < 0.001$ ), female ( $p = 0.001$ ), a non-cancer diagnosis ( $p < 0.0001$ ), poor performance status ( $p < 0.01$ ) and poor prognosis ( $p < 0.001$ ) were all associated with a higher likelihood of achieving PPD ( $p < 0.01$ ). Care home residents with the PPD being the care home was associated with achieving PPD ( $p < 0.00001$ ). A higher proportion of patients for whom a discussion about cardiopulmonary resuscitation had been made with the family, died in their PPD ( $p < 0.00001$ ). Having just-in-case medication was also associated with patients achieving PPD ( $p < 0.0001$ ).

**Conclusion:** A high proportion of patients with an electronic care record and personalised care plan in our system achieved their PPD. There are clear factors which are associated with a greater likelihood of achieving PPD and these need to be explored further in order to increase overall PPD for this population.

Abstract number: FC08.2

Abstract type: Oral

**Preferred Priorities of Care Document in the United Kingdom: Does it always Facilitate a Good Death?***Abbas S.Q.*

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**Background:** In the United Kingdom, a key measure of success of end-of-life strategy is the proportion of deaths that occur at home, as opposed to in hospital. To facilitate this, the 'Preferred Priorities of care' (PPC) document was introduced. However, there have been cases when the spirit of this measure is compromised by ignoring the clinical need or appropriateness of surroundings. This paper reviews case studies when PPC was the reason for confusion or was used against its spirit.

**Aim:** To review cases where PPC did not contribute to high-quality care for all adults at the end of life as defined in the end of life strategy.

**Methods:** Hospice patients' notes were reviewed manually.

**Results:** 561 new community referrals were received over one year. 265 deaths were observed. 67% had their PPC documented. Critical cases were noted with following themes:

- 1) Disagreement between patient and family about place of care
- 2) Family's unawareness of patient's preferred place
- 3) Patient's unawareness of the right of being able to be cared for at hospital for other health-related issues, when they decided that preferred place of care was home
- 4) Family over-ruling of patient's choice when patients lost capacity
- 5) Family's unwillingness to support preferred place of care as preferred place of death
- 6) Lack of services in community to meet preferred place of death
- 7) Lack of education of community staff to achieve a good death at home
- 8) Staff coercion to alter paperwork to achieve death in another place, as not achieving preferred place of care was perceived as failure.

**Conclusion:** Evidence suggests that although achieving death at a place of choice is a tool for 'good death', it is not always a rule. If not handled sensitively, it can lead to difficult deaths. Open and honest discussions are needed with training for staff to hold such discussions. Also, discussion about preferred place of death should be a part of discussion of advanced care planning rather than an isolated discussion.

Abstract number: FC08.3

Abstract type: Oral

**The Art of Interweaving Clinical Activity to Strengthen Care Provision: The Tapestry Reflecting Technology Use in End of Life Care***García-Baquero Merino M.T.<sup>1,2</sup>, Santos Puebla D.<sup>2,3</sup>, Pinedo F.<sup>3</sup>, Pinto Garzon M.<sup>4</sup>, Quiros Navas E.<sup>3</sup>, Molina Cara C.<sup>3</sup>, Gil Higuera E.<sup>2</sup>, de Luis V.<sup>2,5</sup>, García Adrián S.<sup>2</sup>, Ruiz López D.<sup>2</sup>, Monleon Just M.<sup>2</sup>, Hernandez del Castillo J.<sup>2</sup>*

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**Background:** Patient and family centred palliative care (PC) must be organised around needs and their complexity. To be truly effective, services ought to be available 24 hours a day, which present a challenge to policymakers, managers and professionals alike.

**Aims:** To describe the evolution and consolidation of a PC service and information platform offering care and resources allocation. To assess the effectiveness of pulling together regional activity in a convenient way to facilitate decision making at multiple levels.

**Methods:** Retrospective descriptive analysis of 4 years data collected through agreed Minimum Data Set (MDS) in own database collected by all regional PC teams.

**Results:** Over the 4 years, most regional palliative care has been collected monthly, we show it joined now. The central PC platform has established some 70,000 contacts. During the last 6 months after it started giving access to PC resources, other than advice and support, workload has increased: 15795 contacts of which 41% were from family and carers, 24% from PC support teams; 2.8% support and advice to emergency services among others. The 24 teams themselves established over 5,000 contacts broken into patient and family support, feed back to other teams related to resource availability. Activity: Home care teams saw a 7.9% increase in number of patients. Hospital support teams saw a 4.19% increase. Independent sector bedded units saw a 4.94% and Public bedded Units 20.49%.

**Discussion and conclusion:** A central single point of activity collection is effective and informs policy-making. Investing in a robust technology frame applied to PC development is cost-effective. Home care and death have increased over the past 4 years in our setting while bed use has increased as has their turn over, ensuring effective use of resources. As a whole our PC provision has significantly extended. Single patient tracking through the system is our next goal; it depends on protocol completion.

Abstract number: FC08.4

Abstract type: Oral

**'No One is Joining all the Dots': Partnerships between Patients, Family Caregivers and Health Professionals in the Transition to Palliative Care***Fox J.A., Yates P., Windsor C., Connell S.*

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**Background:** The transition to palliative care is a complex process. Best practice incorporates comprehensive support of patients and family caregivers incorporating a patient centred team approach.

**Aims:** In this paper we explore the process of transition to palliative care within an acute care setting to make visible the contextual conditions within which the transition is constructed and negotiated. A preliminary analysis that identified tensions between the theory and practice of palliative care was previously reported.

**Methods:** A critical approach informed the research. The methods involved semi structured interviews with sixteen patients and family caregivers and thirteen health professionals thus ensuring a broadly based view of the complexities of the transition process.

**Results:** The key findings depict a complex intersection between acute and palliative care. Despite the rhetoric of multi and interdisciplinary team approaches, entrenched professional boundaries restricted the provision of continuity of care. Furthermore, in the acute setting, palliative care was constructed around the political and professional interests of different specialties and as such there were no clear pathways for patients. The research findings depict a conflicting interplay between oncologists as generalists in providing a palliative approach and specialist palliative care services. The timely identification of patients and initiation of conversations about palliative and end-of-life care were found to be difficult for generalist clinicians.

**Conclusions:** The findings point to the need for stronger and more coherent partnerships between patients, family caregivers and health professionals. This would mean more permeable professional boundaries that allow for an efficacious interdisciplinary approach to the transition to palliative care. The findings will inform the service development needed to improve palliative care services in the acute care setting.

Abstract number: FC08.5

Abstract type: Oral

**A National Approach to Palliative Care Education: Developing a Harmonised Suite of Courses Lego Style for Different Settings, Specialties and Disciplines***Pereira J.L.<sup>1,2,3</sup>, Downer K.A.<sup>3</sup>, Kelley M.L.<sup>4</sup>, Ray N.<sup>3</sup>*

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Patients facing life-limiting illnesses often experience sub-optimal care. Symptoms and psychosocial-spiritual needs are inadequately addressed and honest discussions regarding prognosis and end-of-life care preferences are done too late or not at all. Palliative care (PC) is misperceived as only end-of-life care, missing opportunities to reduce symptom burden and improve treatment choices earlier in the illness. Health professionals including family physicians and specialists should possess core competencies to initiate and provide basic palliative care.

A Learning Essential Approaches to Palliative Care workshop will present an inter-professional clinical introduction to PC that describes core modules on key topics and a constructivist approach to design that incorporates theory bursts, case and problem-learning and trigger videos. Courseware redesign reflects new evidence and encompasses different settings/specialties.

Competencies common and unique to different settings and a series of new 'building block' thematics to address specialties of care include: Long-Term Care, Emergency Departments, Acute Care Hospitals, Oncology, Surgery, Hospices, Aboriginal communities and end-stage organ diseases. A peer-reviewed referenced Palliative e-pocket book/app will be showcased. Through a website portal certified facilitators can tailor-make their workshops to specific learner needs, using a Lego-block assembly approach.

Course evaluations on curriculum content, design and large scale implementation, plus PhD research found significant improvement in pre-versus post-course assessments of



knowledge, skills and attitudes. Content and delivery considerations include: evidence informed, competency aligned, quality assured, consistent pan-Canadian approach, responsive to local context, respecting whole person, dignity-enabling and amelioration of suffering, and population-health oriented information sharing; each critical to developing a National Approach to PC Education.

**Abstract number:** FC08.6

**Abstract type:** Oral

### Integration of Palliative Care: Fiction or Reality? A Systematic Literature Review of Empirically Tested Integrated Palliative Care Models in Europe

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**Background:** Studies in palliative care (PC) in Europe identify four deficiencies in current practices: 1) severely ill patients are frequently transferred between home and other care settings in the last phase of life, 2) patients do not often die in their place of choice, 3) large variations in (non)treatment strategies exist and 4) informal caregivers are at high risk of overburdening. Integrated PC provides a framework for addressing these challenging issues. **Aim:** The objective of this study is to evaluate empirically tested models of integrated PC in cancer and chronic diseases.

**Methods:** Search strategy: Cochrane, PubMed, EMBASE, CINAHL, AMED, BNI, Web of Science, NHS Evidence and Google were searched. Five journals and references from included studies were hand-searched.

**Data collection:** Two reviewers screened the search results. Studies with adult patients with advanced cancer/chronic disease, published from 1995 to 2013 in Europe, in English, French, German, Dutch, Hungarian or Spanish were included.

**Analysis:** Included records were assessed by the numerical scoring system of Hawker for quality and completeness. Due to the heterogeneity of the results a narrative synthesis was used.

**Results:** 24 studies were included, 11 models for chronic disease (dementia, multiple sclerosis, chronic heart failure, renal failure, HIV/AIDS), 5 for integrated care in oncology, 6 for an integrated care protocol for imminently dying patients and 2 for PC services. The results show a strong agreement on the benefits of the involvement of a PC team: better symptom control, less caregiver burden, improvement in continuity and coordination of care, fewer admissions, cost effectiveness and patients dying in their preferred place of care.

**Conclusion:** Joint ventures between PC and disease treatment results in more patients being exposed to early PC in the disease trajectory which enables them to explore their fears, achieve the available support and make advance care plan decisions.

**Abstract number:** FC09.1

## FC09

### Older people, dementia and multimorbidity

**Abstract type:** Oral

### Living Well with Dementia: Enhancing Dignity and Quality of Life, Using a Novel Intervention, Dignity Therapy

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**Background:** Maintenance of dignity and enhancement of quality of life are key, integral elements of care for people with dementia. Meaningful communication with people who have dementia becomes more difficult as the condition progresses. Improvements in communication may have a positive effect on the person's quality of life, with individualised approaches being strengthened by the use of existing strategies such as memory/life story approaches. Dignity therapy is a short psychotherapeutic intervention that uses a trained therapist to take the person through a recorded, guided interview process, to produce a generativity document that creates a lasting, written legacy.

**Aims:** The aim of this feasibility study was to assess the feasibility, acceptability and potential effectiveness of (modified) dignity therapy to improve the quality of life and reduce psychological and spiritual distress in older individuals with early stage dementia.

**Methods:** Mixed methods feasibility study. Data were collected via standard outcome measures, standard demographic measures and a qualitative interview pre and post the intervention (dignity therapy) over a twelve month period, August 2013–August 2014, from a total of 7 people with early stage dementia (9 who completed dignity therapy), 7 family members, 6 key stakeholders and a focus group with 8 people with dementia.

**Results:** This study has shown that dignity therapy is feasible, acceptable and potentially effective for older individuals with dementia; the outcome measures have the potential to indicate changes in quality of life and psychological and spiritual distress as a result of dignity therapy, and are therefore relevant for use in further larger scale study that will evaluate effectiveness. Dignity therapy can provide detail to inform care for the person with dementia. The provision of care that is informed by dignity therapy has the potential to be more person-centred, and therefore enhance dignity for people with dementia.

**Abstract number:** FC09.2

**Abstract type:** Oral

### A Cross-sectional, Retrospective Study Using Nationwide GP Networks of Circumstances of People Dying with Dementia in Belgium, Italy and Spain

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**Background:** The number of people dying with dementia will continue to increase, yet we know very little about their end-of-life circumstances from a broad epidemiological, cross-country perspective.

**Aim:** To examine and compare circumstances of dying among people with dementia in Belgium, Italy and Spain by investigating differences in end-of-life care processes and outcomes.

**Methods:** A cross-sectional retrospective study was conducted using representative nationwide networks of general practitioners in Belgium, Italy and Spain. Patients of participating practices who died in 2009–2011 aged 65 or over were included if the general practitioner judged them to have had dementia (n=1623).

**Results:** GPs reported a higher proportion of older people with severe dementia in Belgium (55%) than in Spain (46%) and Italy (45%), and a higher proportion of patients living in care homes (57%, 18% and 13% respectively). A palliative care goal in the last three months of life was more common in Belgium (72%) and Spain (75%) than in Italy (62%; odds ratio=0.52). Communication between GP and patient was more frequent in Belgium than in Spain (OR=0.29) or Italy (OR=0.15), but even in Belgium a preference for a proxy decision maker was expressed in less than 12% of cases, and for a medical end-of-life treatment in less than 11% of cases. Physical symptom distress was present in more than 85% of cases in Belgium and Spain, and in 66% of cases in Italy (OR=1.23). Almost half of all people in the study were transferred between care settings in the last three months and between 13% and 15% in the last week of life.

**Conclusion:** Though Belgium and Spain show higher levels of communication and palliative care goals, many aspects of end-of-life care for people with dementia can be improved in all three countries. Initiatives to improve end-of-life care in primary care are of particular value for this group.

**Main funding source:** EU Seventh Framework Programme (FP7/2007-2013, grant number 264697).

**Abstract number:** FC09.3

**Abstract type:** Oral

### A Successful Intervention to Improve Quality of End-of-Life Care (QOC) and Quality of Dying (QOD) for Patients with Advanced Dementia

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Most patient with advanced dementia die in long term care institutions. There is a growing consensus that, the more advanced the dementia, the more relevant is palliative care.

**Aim:** To assess a multidimensional intervention to improve QOC and QOD in patients with advanced dementia (stage 7 Reisberg Scale).

**Methods:** The intervention consisted of training the nursing staff and physicians as well as families to the option of symptomatic care approach for end-stage pneumonia and feeding difficulties. Early detection of pain with an observational scale (PACSLAC), early systematic use of mouth care and family support for decision-making were the main components of this intervention. Family values and beliefs were respected in the decisional process. A local nurse trusted by her colleagues and by physicians worked full time as a consultant to implement this approach. The intervention was tested in 4 nursing homes (2 with intervention and 2 with usual care). Primary outcomes were quality of end of life care assessed by family members (Family Perceptions of Care Scale) and quality of dying (CAD-EOL/Comfort Assessment in Dying) assessed by families and nurses. In order to understand which part of the intervention was most useful, four focus groups with nursing staff members were held after completion of the project.

**Results:** In the experimental group, there was a large increase in the proportion of families highly satisfied with care. CAD-EOL scores were also significantly better and compared very favourably with similar measurements in Netherlands, Belgium and USA. Focus group participants mentioned that educational training sessions were not sufficient to induce those changes and that the consultant nurse was very helpful in translating new knowledge into actions.

**Conclusion:** This multidimensional intervention has improved QOC and QOD in advanced dementia. A trained local nurse acting as a consultant appears to be the key element in this intervention.

Abstract number: FC09.4  
Abstract type: Oral

## The Clash of Cultures between Generalists and Specialists in Hospital: An In-depth Ethnography to Improve Access to Specialist Palliative Care for Older Adults

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**Background:** Globally about 20 million people, of which 69% are over 60 years old, need palliative care at end of life. This doubles when including those that would benefit from receiving palliative care earlier in their illness. However, research shows that less than a third of those identified as needing palliative care receive it. Evidence-based recommendations informed by clinical expertise on how best to enable generalists to refer to specialist palliative care (SPC) is needed.

**Aims:** To identify lead clinical team cultures in hospital settings which may hinder or help access to SPC for older adult patients.

**Methods:** An ethnography in three hospitals in London, UK was conducted, involving in-depth, semi-structured interviews with SPC and generalist staff sampled purposively, transcribed verbatim, and analysed using open and axial coding.

**Results:** Three lead clinical team cultures were identified that may hinder timely or appropriate access: curative, where curative treatment is prioritised and access to SPC is limited until the end of life; self-sufficient, where palliative care is provided by the lead clinical team and SPC is not readily consulted; and over-reliant, where SPC is too readily consulted when staff feel out of their depth, restricting service allocation to others. One lead clinical team culture supported access: collaborative, where a clear partnership is apparent between the lead clinical team and SPC.

**Conclusions:** Cultural change requires a multi-pronged approach that focuses on values, attitudes and knowledge as well as structure, processes and outcomes. To begin, staff education is needed to ensure access to patients who would benefit from SPC alongside disease-modifying treatment for curative cultures. Clear SPC referral criteria and service scope is required for self-sufficient and over-reliant cultures. Dissemination of the success of the collaborative model is recommended.

**Funders:** Atlantic Philanthropies, Cicely Saunders International

Abstract number: FC09.5  
Abstract type: Oral

## International Variation in Place of Death of Older Persons who Died from Dementia in Fourteen European and Non-European Countries

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**Background:** The acute hospital setting is considered not to be an adequate setting for end-of-life care or as place of death for patients with dementia, although they are frequently admitted to this setting at the end of life.

**Aims:** To examine variation in place of death of older persons dying from dementia in countries across four continents.

**Methods:** Study of death certificate data of older (65+ years) people whose underlying cause of death was a dementia-related disease (ICD-10: F01, F02, F03, G30) in Belgium, Netherlands, England, Wales, France, Italy, Spain, Czech Republic, Hungary, New Zealand, USA, Canada, Mexico and South Korea. We examined associations between place of death and sociodemographic factors, social support and residential and healthcare system factors.

**Results:** Of 4.8% of all deaths (n=264,604), the underlying cause of death was a dementia-related disease. Of those deaths, the proportion occurring in hospital varied from 1.6% in the Netherlands to 73.6% in South Korea. When controlling for potential confounders a death in hospital was more likely for males, those younger than 80, married or living in a region with a higher number of long-term care beds, although this could not be concluded for each country. Hospital death was least likely in the Netherlands compared to other countries.

**Conclusions:** Place of death of older persons who died from a dementia-related disease differs substantially between countries, possibly reflecting organisational differences in end-of-life care provision. Increasing the availability of long-term care beds might be important to reduce the number of hospital deaths, while providing specialised end-of-life care to those aged 65–79 or married in particular might be crucial for increasing the proportion of home deaths. However, proper end-of-life care needs to be ensured in hospitals, should this be the most appropriate end-of-life care setting.

Abstract number: FC09.6  
Abstract type: Oral

## Hoping, Coping but Not Planning: The Contradictions of Living with Advanced Multimorbidity

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**Background:** Many people now die with multiple advanced conditions (multimorbidity) but their palliative care needs are poorly researched. People with advanced cancer are

increasingly likely to be identified for additional supportive and palliative care in contrast to those with one or more advanced, non-malignant conditions.

**Aim:** To explore the lived experiences and coordination of care in the last year of life of patients with deteriorating health from advanced multimorbidity and their family carers.

**Methods:** A multi-centre study combining ethnographic observations for 18 weeks and qualitative, longitudinal interviews over nine months with patients and carers identified in three UK clinical settings: an acute hospital, a large general practice and respiratory outpatient clinics.

**Results:** 56 patients and 25 linked family carers contributed 181 serial interviews. They experienced reactive, unplanned care characterised by uncertainty, acute health crises and difficulty articulating why they needed help in the absence of a single diagnosis. Most tried hard to self-manage their multiple illnesses and medications while seeking to maintain a sense of self and normality. They 'hoped for the best', 'coped' on a daily basis, and largely avoided planning for the future or considering themselves as potential recipients of palliative care.

**Conclusion:** Multimorbidity posed major challenges for professionals and services focused on treating single conditions or acute episodes of deterioration. Patients lacked a clear understanding of their different conditions and were rarely identified for care coordination or anticipatory care planning by any of the multiple services involved. This is the first qualitative, longitudinal study of people's experiences of living and dying with multimorbidity.

Abstract number: FC10.1

## FC10

### Dignity, psychology and bereavement

Abstract type: Oral

## Bereavement Services in Palliative Care in Europe. A Survey Study by the EAPC Bereavement Taskforce

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**Background:** While the WHO definition of palliative care states a responsibility to offer bereavement support, there is no knowledge of the extent of bereavement care provision throughout palliative care services in Europe. There is limited information on the organisation of bereavement care within palliative care in Europe and what informs service delivery.

**Aim:** The aim of this study was to survey bereavement services in hospice and palliative care in order to describe the current bereavement care provided in palliative care services in the EAPC.

**Method:** A questionnaire was developed based on previous studies and piloted by bereavement coordinators. A link to the online questionnaire was distributed via the EAPC to 56 national associations in 32 countries during December 2013 and January 2014. The questionnaire consisted of 54 questions and was available in English and Spanish. It was structured into six sections: background information, activities, personnel, access, community links and funding.

**Results:** There were 370 responses from 25 countries (78%), and 302 (82%) provided bereavement service. Formal guidelines informed organisation of service in 98 (33%) units, and 75 (25%) used a formal risk assessment tool to assess support needs. Bereavement coordinators were employed in 135 (45%) of services, and a wide range of activities were provided, e.g. telephone support 254 (84%), bereavement counselling 244 (81%) and support groups 169 (56%), reflecting a tiered approach.

**Conclusions:** This study presents the first overall picture of bereavement support in palliative care services in the EAPC. One fifth of services did not prioritise bereavement care as an integrated part of the palliative service. The results indicate a range of support activities, however only one third of services used validated risk assessment or formal guidelines. It seems timely for the EAPC and palliative care services to formalise their approach to bereavement to secure quality of care.

Abstract number: FC10.2  
Abstract type: Oral

## The Bereavement Experience of Lesbian, Gay, Bisexual and/or Transgendered (LGBT) People: A Systematic Review and Meta-synthesis of the Literature

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**Background:** Although socially excluded populations have poorer access to care, little attention has been paid to lesbian, gay, bisexual and/or transgendered (LGBT) people. A systematic review identified that although at higher risk of certain life-limiting illnesses, LGBT people may not access the care and support they require at the end of life due to fears of discrimination. A recent survey found that 48% of LGB people fear discrimination when facing bereavement.

**Aims:** To identify and appraise the existing evidence of the bereavement experience of LGBT people whose partner died.

**Methods:** A systematic search was conducted in October 2014 of five major electronic databases: PsychInfo, Medline, Web of Science, Scopus, and Cochrane Library. Meta-synthesis was used to integrate the results.

**Results:** Based upon strict eligibility criteria, 27 papers were identified, reporting primary data about the bereavement experience of LGBT people who have lost a partner. The impact of HIV/AIDS continues to permeate the LGBT bereavement literature. Studies reported commonalities of losing a partner, between LGBT and heterosexual relationships, including

struggling to find purpose in life post bereavement. However key themes reported for bereaved LGBT people included disenfranchised grief, and lack of social support, described through experiences of: exclusion, invisibility, lack of involvement in decisions and funerals, assumptions of HIV/AIDs and being forced to disclose sexual identity in order to acknowledge their grief. Relationship with the partner's family was significant in shaping the experience. Within the literature the experience of bisexual and transgendered people was poorly represented, and was usually absorbed within larger LG studies.

**Conclusion:** Challenges accessing services, and a lack of recognition of LGBT relationships, indicate a need to improve access to, and supply of, bereavement support for LGBT people.

**Funding:** Marie Curie Cancer Care.

**Abstract number:** FC10.3

**Abstract type:** Oral

### Psychological Distress in Palliative Care: Analysing the Symptoms of the Identity Crisis

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Psychological distress is experienced by 60% patients with advanced disease (Roth and Breitbart, 1996). It's a challenge for palliative care (Chochinov *et al*, 2009). It becomes a burning issue in society and raises debates with answers such as euthanasia and induced coma. This quantitative and qualitative study aims at investigating this distress through the encounter of psychologists with their patients. According to Rodin and Zimmerman (2008) patients experience an identity crisis generated by the lethal disease. This study verifies the assumption of a link between an identity crisis and distress. More broadly this thesis analyses the therapeutic function of psychological interviews offered to patients.

**Method:** During one year, 14 psychologists used a booklet as a guidance on a grid of concepts, to collect representations of their patients' mental processes, cons-transfer mechanisms and maintenance functions. Several measuring tools have been used: qualitative ordinal board for losses caused by illness, visual analogic scales, a qualitative categorical board for breaks identity, the Clinical Global Impression (CGI-3) to evaluate the therapeutic effect and free notes. A second group of 12 psychologists across France reiterated the experience. Statistical analysis has been performed with STATA 10.0 and Alceste software.

**Results:** 1115 interviews conducted among 339 patients aged 68 on average (25–95) demonstrated the lethal disease generates an identity crisis experienced by the patients as a feeling of distress ( $b=0.53$  [0.39–0.66],  $p<0.05$ ). Furthermore, the longitudinal course of the interviews shown a potential transformation of the patient's identity and a reduction of his distress.

**Discussion:** Inter-subjectivity interviews and palliative care allow to restore self-awareness for the dying patient.

**Conclusion:** Distress can be reduced if a therapeutic framework is proposed to accompany the identity rupture.

**Abstract number:** FC10.4

**Abstract type:** Oral

### Relationship between Perceived Dignity and Autonomy at the End of Life: Results of a Meta-ethnographic Study

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**Introduction:** Various studies in the end-of-life context have explored the sense of dignity (SD) experienced by elderly people or patients with advanced disease, examining the factors associated with it. Whereas certain philosophical perspectives regard personal dignity as an intrinsic quality that is independent of external factors, in the clinical setting it is generally equated with the person's sense of autonomy and/or control over life's circumstances. Although safeguarding a sense of dignity and autonomy among patients is a key objective in clinical practice, there has to date been no systematic review of the literature on this topic.

**Aims:** To conduct a systematic review and meta-synthesis of primary qualitative studies examining autonomy and control as mediators of SD in patients at the end of life.

**Methods:** The search strategy used MeSH terms in combination with free-text searching of the Pubmed, WoK, CINAHL, PsychInfo and Cochrane databases. This identified 186 articles, after excluding duplicates. Twenty-one studies were finally included in the review and were evaluated using the CASP tool. The qualitative synthesis followed the methodology described by Noblit and Hare.

**Results:** Three categories emerged from the analysis: dignity as personal identity, dignity mediated by loss of functional ability, and autonomy as the basis of dignity. The main mediators of a diminished SD were loss of functional ability, perceived dependence and fragility. The social factor was a common theme across categories and was especially linked to perceived self-identity.

**Conclusions:** The SD is a complex construct that emerges as an expression of what it is that gives value to these patients' lives. An in-depth understanding of the experiential context may help to ensure these patients are not reduced to their circumstances, thereby improving their quality of life.

**Abstract number:** FC10.5

**Abstract type:** Oral

### Adapting Meaning-centred Psychotherapy for a Palliative Care Setting: Results of a Pilot Study

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**Background:** The effectiveness of meaning-centred psychotherapy (MCP) as an intervention for helping improve quality of life and reduce psychologist distress among patients with cancer is steadily growing. However, applying mental health interventions to the palliative care setting raises a number of challenges, including the role of fatigue, confusion, and even denial.

**Aims:** The goal of this study was to investigate the feasibility, acceptability and effectiveness of an abbreviated version of for the palliative care setting (MCP-PC). Unlike past research using MCP, which involved 7–8 weekly sessions, we developed a treatment manual that required only 3 sessions, each lasting roughly 30–45 minutes.

**Methods:** Patients with stage IV cancer admitted to a palliative care hospital for end-of-life care participated in a 3-session intervention aimed at helping improve psychological and spiritual well-being. Patients were administered the Distress Thermometer (DT) and the Hospital Anxiety and Depression Scale (HADS) prior to study entry, and completed a post-treatment questionnaire assessing their perception of the treatment. Only those patients who were sufficiently alert and deemed by the treating physician to be appropriate for study participation were eligible.

**Results:** Preliminary results ( $n=7$ ) indicate a high degree of acceptability and perceived utility for IMCP-PC. Pre-treatment DT scores ranged from 0 to 10 and HADS scores ranged from 4 to 23; 3 participants had clinically significant levels of distress. All patients completed the 3 sessions, but requests to reschedule sessions occurred frequently, typically due to fatigue or the presence of visitors. All participants reported considerable benefit from the intervention.

**Conclusions:** The need for effective, rapid and feasible interventions for palliative care patients is clear, but is fraught with logistical challenges. This presentation will discuss the results of this pilot intervention.

**Abstract number:** FC10.6

**Abstract type:** Oral

### Life Values of Older Advanced Cancer Patients (70+). A Qualitative Study to Improve Care in the Last Phase of Life

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**Background:** Society is confronted with an increase of elderly patients with advanced, incurable cancers. Little is known about these patients' life values, whether they are age-specific, and how to attune end-of-life care to these values.

**Aims:** To investigate age-specific life values of older advanced cancer patients (70+ years).

**Methods:** In a qualitative study, older advanced cancer patients' life values were collected with semi-structured qualitative interviews ( $n=16$ ). Then, these life values were discussed from an end-of-life care perspective in two care professional focus groups.

**Results:** Older advanced cancer patients' attitudes on their future switched between giving oneself up to an inevitable uncertainty and actively bringing order into the chaos. The latter meant focusing on a 'normal life' (and demanding from others to act accordingly) and/or intensifying social contacts in search for meaning of life and death. Patients also nursed hope to maintain a functional status quo and/or hope for a miraculous cure to address uncertainty. Nevertheless, end-of-life arrangements (among which euthanasia) were already in preparation in case degrading decay and social isolation would prevail. Most patients thought that death is an appropriated ending to a long/meaningful life. Furthermore, living in the face of death induced retrospection on social impact. The attention received from proxies during the illness was a measure of positive impact.

**Conclusion:** Some results could be related to older age: older patients seemed free from large social responsibilities (e.g. young children) and aspired to continue to live a simple life. Except for those who bear responsibility for a sick partner. Attention from children and friends in the last phase of life confirmed social impact and having lived a meaningful life. Knowledge of these life values will support the development of a serious game that improves end-of-life care communication.

Funded by Dutch Cancer Society

**Abstract number:** FC11.1

## FC11

### Policy and economics

**Abstract type:** Oral

### Multi-layered Learning – A Mechanism to Translate End of Life Policy into Practice

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**Background:** The implementation of end-of-life care interventions is promoted within English healthcare policy to improve care delivery within different settings. How these interventions are best implemented is less clearly promoted. One end-of-life care initiative recommended by the English Department of Health is the Gold Standards Framework in Care Homes (GSFCH) programme. Only a small number of homes complete the programme which raised questions about the implementation process.

**Aim:** To identify the role of facilitation when implementing the GSFCH within nursing care home practice.

**Methods:** A mixed methods study was undertaken within 38 nursing care homes



undertaking the GSFCH programme in England. Qualitative and quantitative data were collected from staff employed within (home managers and GSFCH coordinators) or associated with (external facilitators) these nursing care homes and included interviews, surveys, Facilitator Activity Logs and a researcher's diary. Following separate quantitative (descriptive) and qualitative (thematic template) data analysis the data sets were then integrated by 'following a thread'. Utilisation of a system-based-framework enabled the wider context of the participating nursing care homes to be considered.

**Results:** Three approaches of facilitation were provided to nursing care home staff when implementing the GSFCH programme: 'fitting it in' facilitation; 'as requested' facilitation; and, 'being present' facilitation. Completion of the GSFCH programme, through to accreditation, was significantly influenced by the approach of facilitation that was provided. Implementation of the programme required an external facilitator who could mediate multi-layered learning at an appreciative system level, an organisational level and at an individual level.

**Conclusion:** Multi-layered learning was required to achieve cultural change. It enabled the translation of end-of-life care policy into practice.

**Abstract number:** FC11.2

**Abstract type:** Oral

## What Concept of Good Death Is Motivating English End-of-Life Care Policy?

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**Background:** The National End of Life Care Strategy (NEOLCS) for England and Wales was released in 2008. A guiding principle within it is that people should be able to have a good death. Services are being redesigned to accommodate this goal. Yet, the concept of good death can be contested and is not universally accepted.

**Aims:** To identify the qualities of a 'good' death according to end-of-life care policy.

**Methods:** Discourse analysis of the NEOLCS, policy events related to the NEOLCS, and interviews with 10 policy-makers involved in creating and/or implementing the NEOLCS (primary data collection conducted from 2010–2012). Analysis focused on the values attributed to different kinds and categories of dying and death represented in the text and narratives.

**Results:** The NEOLCS includes an explicit definition of a good death focused around the individual. The wider discourse presents a more complicated definition of what a good death looks like. This includes the place of death, awareness of dying, control of dying, maintaining personhood, and teamwork. Whilst the individual is still important, this definition is more interactionist as it involves the dying person, their family and carers, health and social care professionals, and the general public. At times, the different values may conflict one another.

**Conclusion:** What values are attributed to a 'good death' extend beyond the explicit definition of 'good death' within the NEOLCS. This wider definition, which at times includes contradictions, is being used to shape healthcare services. It is being used to create a standard to evaluate the care of the dying.

**Abstract number:** FC11.3

**Abstract type:** Oral

## The Processes for Modifying Narcotic Regulations towards Increasing Access to Pain Relief – An Indian Experience

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**Background:** India is the biggest producer of narcotic-substrate for pain medications, but its needy millions with severe persistent pain do not have access to these medications. This is due to negligible availability and the lack of awareness and training amongst professionals regarding medical usage of opioids. The fact that India's Narcotic Drugs and Psychotropic Substances (NDPS) Act retained many of the restrictive clauses from the pre-independence Opium policy, was a chief contributor. Several strategies were developed and succeeded in amending the NDPS Act in 2014. The new law is expected to improve the situation of access to pain relief to 1/6<sup>th</sup> of world's population.

**Aim:** To describe systematically, the processes involved in successfully amending the narcotic regulations in India.

**Method:** Qualitative analysis based on interviews of key persons involved, analysis of official documents, reports and letters.

**Results:** Five sequential strategies emerged from the analysis: clarity on narcotic policy being the barrier and the decision to amend the regulatory language, identification of the critical gaps within the Act, modifying it's language to expand the scope including medical and scientific usage, getting the proposal for the Amendment admitted for parliamentary review, advocacy and follow up of the amendment bill during successive parliamentary sessions until its successful passing.

Additional dynamics that facilitated the process were also recognised such as the role of an expert consultative committee at the centre, ongoing public interest litigation on the same issue at the Supreme Court, support from the high offices of 'National Advisory Committee', unified efforts from various sectors in the country and committed participation of international agencies.

**Conclusion:** The processes of changing an archaic law in a large democratic country can be understood analytically through its processes and may be used as a model for other countries.

**Abstract number:** FC11.4

**Abstract type:** Oral

## Policy Barriers to Opioid Access in Eastern and Central Europe: Outcomes of ATOME

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**Background:** The problem of inadequate pain relief has drawn the attention of the international community, increasingly viewed as a violation of basic human rights. While barriers to opioid availability are complex including restrictive laws, regulations and licensing requirements, a key problem that limits the distribution of controlled medicines relates to policy.

**Aims:** To examine policy barriers to opioid availability for pain management and palliative care in twelve countries in Eastern and Central Europe involved in ATOME, a European Commission FP7 funded project (no 222994) aimed to improve Access to Opioid Medication across Europe.

**Methods:** A systematic content analysis of documents (n=5 or more) developed and submitted during ATOME including protocols of national problem analyses, strategic planning worksheets, executive summaries and minutes of national conferences and six-country workshops held between March 2012 and April 2014 was performed.

**Results:** Twenty-five provisions of policy barriers (e.g. economic crisis, bureaucratic issues, inadequate continuing medical education, stigma and discrimination) were identified. Based on the total number of identified provisions, Estonia and Latvia ranked first on the list (20) followed by Greece (19) and Slovenia (18) whereas Hungary (13) and Turkey (11) ranked last. Provisions related to education and training (absent, limited or fragmented education, lack of training initiatives) and societal attitudes (fears, lack of awareness and inadequate social dialogue and dissemination) appeared to be highly prevalent observed in all countries involved in ATOME.

**Conclusion:** Improving access to opioid therapy for quality pain management and palliative care in Central and Eastern European countries requires policy reform at governmental level. It is therefore essential that a set of action plans related to economic, education and social policy is developed and systematically implemented to guide such a reform.

**Abstract number:** FC11.5

**Abstract type:** Oral

## Developing a National Public Health Service as a Compassionate Employer

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**Background:** Most working people will experience caring for the dying and bereavement. As life expectancy increases, more working people find themselves in the 'sandwich' generation caring for both children and elderly relatives. There is a strong evidence base on physical and psychological health effects of caring for dying relatives (1). This caring role is disproportionately borne by women. The National Public Health Service has a leadership role in developing and supporting public health initiatives to improve the care of the dying and carers in the population including prevention of avoidable morbidity. The development of compassionate employers is a strand within Compassionate Communities.<sup>1</sup>

**Aim:** To develop a National Public Health Service as a compassionate employer and as an exemplar for a national initiative within the Compassionate Communities Approach.

**Methods:** The evidence base for health effects of caring, the rationale for being a compassionate employer to mitigate these effects, the demographics of the workforce, legal and organisational position with respect to carers leave and compassionate leave were summarised. Staff engagement was sought from the chief executive, directors, trade unions, HR, occupational health and from key grass roots employees. A session on public health approaches to dying was held at the National Scientific Conference. Support was provided by a national Charity.

**Results:** Support was gained from the CE and top team and incredible grass roots enthusiasm supported by the trade unions. Policies were reviewed. This was taking place at a time of reorganisation, austerity and cuts and the concept of compassion started to spread through other components of policy. A guide was produced for other employers.

**Conclusions:** The development of Compassionate Employer status stimulates discussion of death and dying as a public health issue with wider ramification beyond the focus on death. 1. Compassionate Communities Toolkit website

**Abstract number:** FC11.6

**Abstract type:** Oral

## Dilemmas in Palliative Care Development: A Comparative Enquiry in the USA and England

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**Background:** Delivering optimal and equitable care to people with palliative care needs is an international challenge.

**Aim:** To evaluate the current status of palliative care (PC) development in the USA and England, drawing attention to differences and similarities in: service organisation, key concepts, challenges perceived by stakeholders and future directions.

**Methods:** The authors had exchange visits to England and USA, spending 4–6 months evaluating PC development in their host country via informal interviews with key stakeholders, who included policy makers, practitioners and field leaders (n=20 in the USA and n=35 in England) and a narrative review of relevant research and policy documents.

**Results:** There is conceptual confusion in both countries about the meanings of 'palliative', 'hospice' and 'end of life' care and their relationship. While the organisation, delivery and funding of hospice care is radically different, in both countries hospice care remains closely associated with terminal care, although there are signs of reform. Formal palliative care plays a minor role in delivery of end of life care for the majority of those who die or in the ongoing

health and social care of people with life limiting/ threatening conditions. This has major implications for the adoption and development of public health strategies for palliative care. **Conclusions:** Despite fundamental differences in the financing and ownership of healthcare in the two countries, many policies, practices and challenges for PC are comparable. Lessons learned can be applied not just in these two countries but for many others as well.

**Abstract number:** FC12.1

## FC12

### Medical sociology

**Abstract type:** Oral

#### Room for Death – Museum-visitors' Preferences Regarding the End of their Life

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Data is lacking on how the general public conceptualises 'good death' at this time in history. This presentation aims to discuss such data, generated from an international general public. Data derives from a project which teamed 5 pairs of artists and craftsmen together to create prototypes related to space for difficult conversations in end-of-life (EoL) settings. These prototypes were presented in an exhibition, 'Room for Death', at the Architecture and Design Center in Stockholm from June–Sept 2012. Through their role as project consultants, palliative care (PC) researchers contributed a question directed to the public viewing the exhibition, to explore their reflections: 'How would you like it to be around you when you are dying?' This question, in Swedish and English, was placed in a central place at the exhibition, for documenting reflections if so desired.

The 512 responses were obtained from visitors from 46 countries, with most from Sweden, followed by the US, France, Germany and Italy. While preliminary analysis pointed to many similarities in idealisations of death across countries, continued analysis with a phenomenographic approach allowed us to distinguish different foci in how ideal death is conceptualised. Of the responses analysed, nearly 95% were categorised in one or more of the following eight categories: the 'lone' death, the 'mediated' death, the 'familial' death, the 'larger-than life' death, the 'calm and peaceful' death, the 'sensuous' death, the 'green' death, and the 'distanced' death. These categories of conceptualisation will be further elaborated in relation to what is and is not seen in these data, and implications for the development of palliative care research and practice discussed.

**Abstract number:** FC12.2

**Abstract type:** Oral

#### The 'Message' of Palliative Care in Spain. A Mix-method Analysis of the Printed and On-line Press

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**Background:** Mass media are the main agents in the process of building public opinion and frequently deal with Palliative Care (PC) thereby contributing to its image and public understanding.

**Aims:** To explore and describe the circulating ideas and messages about PC in Spanish print (PT) and on-line (OL) media.

**Methods:** Attending to dissemination criteria and plurality of editorial lines, four national PT (El País, El Mundo, ABC, La Vanguardia) and four OL newspapers (Elconfidencial.es; Lainformación.es; Publico.es; Libertaddigital.com) were selected. Through a repository of all national newspapers (MyNews) and each newspaper database, all articles published between 2009 and 2014 including the terms 'palliative care' or 'palliative medicine' were identified and full-text obtained. Two analyses on the articles collected were performed: 1) quantitative analysis of the news (through a questionnaire) and 2) qualitative content analysis.

**Results:** 524 articles were identified (260 PT, 264 OL). PT articles were included in the 'National' (37%), 'Society' (33%), 'Opinion' (18%), 'Letters to the Editor' (8%) and 'Health' (3%) sections. Most of the articles are informative (90%), with social message (85%) and nearly half of them include professional testimonies (57%). Qualitative analysis showed how rarely articles address or provide specific information about PC (purpose, activity, etc.), being used in an instrumental way to address issues related to health management and policy/social context. The message and ideas related with PC focus principally on the process of death and only occasionally on the benefits for patients, often eclipsed by social debates related to issues such as euthanasia or the concept of dignified death.

**Conclusions:** Although there is a substantive presence of PC in the Spanish press, ideas and messages associated with it are far from clinical practice and rarely linked to the contributions it can make to patient's quality of life and their environment.

**Abstract number:** FC12.3

**Abstract type:** Oral

#### Living Alone, Dying at Home? A Retrospective Data Analysis of a Specialist Palliative Home Care Team (SPHCT)

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**Background:** There is an increasing number of patients living alone. Palliative care aims to support patients to die in their preferred place of death irrespective of their living situation. **Aims:** The aim of this study was to compare the preferred place of death and support from a SPHCT of patients living alone or with relatives.

**Methods:** Retrospective chart review of patients, followed by the SPHCT of the University of Munich from 10/2009 to 12/2013. We compared patients living alone or with relatives using non parametric Mann-Whitney-U-Test for the following items: preferred place of death, who was present during the terminal phase, time of attendance by the SPHCT, intensity of support, number of on call contacts with the SPHCT and number of emergency doctor visits. The significance level was  $p < 0.05$ .

**Results:** Of 796 patients cared for by our team, 44 were living alone. Of the latter, 30 patients (75%) died at home. During the terminal phase, 14 patients were supported by their children (46.7%), 4 by friends (13.3%), and 2 by 24h nurse (6.7%), 10 patients had nobody in the house and died alone at home (33.3%). The preferred place of death was fulfilled in 36/44 patients (81.8%). In the group with relatives, the preferred place of death was fulfilled in 639 patients (80.3%). Time of support by the SPHCT (days) was longer in the group of patients living alone ( $140.7 \pm 214.8$  vs  $54.7 \pm 87.3$ ;  $p = 0.003$ ). The two groups did not differ in care intensity measured in average hours of contact per day ( $0.95 \pm 0.79$  vs  $0.87 \pm 0.70$ ;  $p = 0.752$ ); number of on call duty contacts per day ( $0.15 \pm 0.34$  vs  $0.08 \pm 0.29$ ;  $p = 0.102$ ), and number of emergency doctor visits per day ( $0.022 \pm 0.15$  vs  $0.027 \pm 0.16$ ;  $p = 0.681$ ).

**Conclusion:** Patients living alone can still die at home if this is the preferred place of death. Although the support from a palliative home care team might be necessary for a longer time, the care is not more intense or more complicated.

**Abstract number:** FC12.4

**Abstract type:** Oral

#### Space and Place for End-of-Life Care: A Photo-elicitation Study

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In our prior research, palliative care (PC) staff documented many activities they carried out in end of life care related to 'creating an esthetic, safe and pleasing environment'. However, little is written about how patients' perceive their surroundings at the end-of-life (EoL). We therefore aimed to learn about people's experience of their surroundings in EoL care by using photo-elicitation interviewing (PEI).

Twenty-three people in 3 PC inpatient units in 2 Swedish cities, 1 PC home care service, and 1 residential care home participated in the study. Participants were given a digital camera and asked to take 3 pictures of that which was meaningful for them in their surroundings.

The interviewer later viewed the photographs with the participant, initiating an interview by asking: "what is this picture of?" and "why did you take it?" Data was analysed qualitatively, focusing on 'space', i.e. the physical, analysed as the researchers' view of the photographs' content, and 'place' i.e. lived experience of the setting, based on framework analysis of interviews with participants about their photographs.

The space most often captured in photographs was private space around the sick person, often within reach of the bed. Analysis of place as described in participant interviews indicated the salience of three themes: an integrated experience of 'Aesthetics of place'; 'Negotiating space', related to how changes in physical function are supported, compensated and overcompensated for; and 'connecting time, expanding space', involving connections to places beyond physical reach and involving the past, present and future. PEI provided explicit examples of how people creating meaning in relation to and through their surroundings. These themes will be elaborated, and we will conclude by discussing limitations and strengths of PEI in EoL settings, including offering an alternative form for communication as verbal ability decreases and fatigue and symptom burden increases.

**Abstract number:** FC12.5

**Abstract type:** Oral

#### A Doctor's Dilemma: Is it Appropriate to Attend a Patient's Funeral?

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**Background:** The death of a patient poses several dilemmas to medical practitioners. Among these is the appropriateness of attending a patient's funeral. Despite anecdotal accounts, as well as general surveys on professional bereavement practices, little is known about why doctors choose to attend, or not, the funeral of their patients. This study sought to understand the factors associated with funeral attendance.

**Methods:** This work is based on data from a survey study of 1098 Australian health professionals. The presentation focuses on the doctors who participated in the survey ( $n = 437$ ). An online questionnaire developed by the researchers was distributed through several Australian health professional organisations between June and December 2013. Responses were voluntary, anonymous and confidential.

**Results:** The majority of doctors were from palliative medicine (25%), general practice (GP) (25%), surgery (19%) and intensive care (15%). Up to 71% of GPs, 67% of oncologists, 67% of psychiatrists, 63% of palliative medicine specialists, 52% of surgeons, and 22% of intensive care specialists had attended funerals. Significant differences in demographics and between specialties were identified in terms of barriers and benefits associated with funeral attendance. A logistic regression predicted funeral attendance by,

- a) the belief that attending funerals was an aspect of self-care,
- b) age,

c) paying respects to the family, and  
d) informing colleagues about own funeral attendance practices.  
Non-attendance was predicted by,  
a) the belief that attending funerals blurs the boundary between the personal and the professional, and  
b) feeling uncomfortable with death.  
**Discussion:** While attendance at patient funerals appears to be a personal decision, the findings of this study emphasise the need for open discussions in medical education and professional development concerning death and the role of doctors after a patient dies. Limitations and future directions will be discussed.

**Abstract number:** FC12.6  
**Abstract type:** Oral

### The Role of Code Status in the Triage of Hospitalised Seriously Ill Patients to Intensive Care: A Qualitative Study of Internists' and ICU Doctors' Experiences

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**Aims:** Triage to intensive care for seriously ill patients is complex. When doctors don't know the patient they rely on code status (CS) to help the decision. We explored internal medicine (IM) and intensive care (ICU) doctors' experiences about the role of CS during the admission process.  
**Methods:** Individual, in-depth interviews with 12 IM and 12 ICU doctors. Doctors reflected on their experiences of ICU admission decision-making. The analysis focuses on CS as a factor influencing the process.  
**Results:** Determination of CS is based on patient preferences, assessment of the context, and preferably on discussions with other colleagues. CS is considered a core facilitator in the triage process, especially at night and during the week-end. Both IM and ICU doctors expect the doctor in charge to routinely discuss goals of care and to write the CS. When the admission decision is not straightforward, doctors meet with difficulties if there is no CS or if the CS is discrepant with their assessment of the clinical situation. When the patient is full code, going against the instruction is perceived to be difficult for three reasons: the referring IM and the ICU doctors do not know the patient, whereas the doctor in charge decided on the code after careful consideration, and intensive care is the patient's only chance of survival. Strategies to solve the associated tension are:  
1) reliance on the ICU doctor's expertise  
2) shared decision making  
3) recognition that questioning the CS is legitimate  
4) existence of a general consensus about situations when ICU is justified (default decision in the absence of CS, acute event linked to iatrogenicity, some diseases (e.g. malignant hemopathies).  
**Conclusions:** Code status is central to the time-pressured decision making about admission of a seriously ill patient to intensive care. Doctors feel uncomfortable if it is absent or perceived to be unreliable. Goals of care should be clearly documented to substantiate a patient's code status.  
**Abstract number:** FC13.1

accounted for 6% and 10.5% respectively.  
**Conclusion:** Increased disease load, pain and depression were all detrimental to QoL, with depression being the strongest predictor of QoL. This underscores the importance of attending to depression symptoms in palliative care settings to ensure best possible QoL.

**Abstract number:** FC13.2  
**Abstract type:** Oral

### Standard Operating Procedures in Palliative Care for Somatic and Psychiatric Symptom Management – Pilot Assessment of Feasibility and Efficacy

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**Background:** In the care for patients in a palliative care situation it may help to standardise repeating processes like pharmacological symptom oriented treatment. Therefore a multiprofessional panel of experts in the field developed standard operating procedures (SOP) for symptom oriented treatment of dyspnea, pain, anorexia and nausea. The SOPs are used primarily in the palliative care unit and are based on the best existing evidence and clinical experience. Feasibility and efficacy of these SOPs is unknown.  
**Methods:** In a pilot survey, all patients admitted to our ward between February and September 2014 (n=108) were either treated according to SOP or the reasons for deviation from the SOP was recorded. Symptom burden was routinely assessed by proxies (HOPE Symptom & Problem Checklist) and by patients (MIDOS\_2). Both tools use a 4-point Likert scale (0=none, 1= mild, 2=medium, 3= strong).  
For the pilot we assessed symptom burden in a random sample of 30 patients at three time points: on admission, after start of SOP treatment and after 3 days of SOP treatment. Differences were computed by single factor variance analyses with repeated measurement (Greenhouse-Geisser), statistical significance was set to p<0.05.  
**Results:** Treatment according to SOP was possible in the majority of patients (93%; n=28/30). In both cases of deviation from SOP patients refused treatment according to SOP and were treated according to his/her wishes by continuing treatment from before. In most of the patients treatment following the SOP led to therapeutic success ameliorating symptom burden significantly: pain (mean: 1.35 to 0.78 to 0.35, p<0.001), nausea (mean: 0.3 to 0.17 to 0, p=0.045), dyspnea (mean: 1.13 to 0.7 to 0.35, p=0.001) anorexia (mean: 2.13 to 1.39 to 0.52, p<0.001).  
**Conclusion:** Treatment according to our proposed SOPs is feasible and seems to be efficient in a palliative care concept and may foster symptom oriented treatment. More research is needed.

**Abstract number:** FC13.3  
**Abstract type:** Oral

### Prevalence, Development and Treatment of Delirium in a Palliative Care Unit

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**Background:** Delirium (D) is a common symptom in palliative cancer patients at the end of life (EOL). It is essential to address the causes and factors that can be modified to minimise the suffering associated.  
**Aims:** To determine the frequency of D. Describe the patients characteristics with D and compared with those who did not develop, treatment received, survival after diagnosis, and if sedation is needed.  
**Methods:** We conducted a retrospective study with cancer patients admitted in a 6 months period and has criteria for D at admission (DI), or during hospitalisation (DDI), or at the EOL (DT), based on data collected in the clinical history. Patients dying within 24 hours of admission were excluded.  
**Results:** n=213 patients, 54% male, mean age 74, 80% with metastases and with 20 days average stay. Develop D 134 (63%): 69% DI, 34%DD, with a median of 9 days after admission. Present DT 85% (113 of the total, 75 DI and 38 DD). Exceed the D episode and not die with D 15%. We found differences regarding the type of tumor: lung cancer in the group that develops D is higher, 19%: 4%. The most common precipitating factors in D are pharmacological, 90% (opioids, steroids) and metabolic, 70% (dehydration, hypoxia, renal failure). In patients who did not die with D has less steroid drugs and less metabolic factors. Haloperidol was most common used drug. In 197 patients who died, 113 (57%) did so in a state of DT. Sedation in the EOL was 66 (31%) in 52 (79%) the indication was delirium. Need sedation 39% of DT. Treatment of sedation was midazolam (83%). In 89 patients with DI develop as DT (84%); with a median survival of 6 days.  
**Conclusion:** The prevalence of D in our unit is very high due to the low survival rate. Reversibility is low and sedation is unnecessary in 39% cases, although DT it is the most important cause of sedation at the EOL. It seems that patients with lung cancer and taking steroids are more likely to develop delirium in our sample.

**Abstract number:** FC13.4  
**Abstract type:** Oral

### Caring to Know Palliative Care

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**Background:** There is growing awareness of the need to apply quantitative measures to nursing interventions involved in Palliative Care (PC), which focusses on the quality of life of patients and their families coping with life-threatening illness. This research study seeks to develop reliable and valid tools to measure knowledge, attitudes, emotional coping abilities and intentional behavior in PC clinical situations.  
**Aims:** The aims are to assess the emotions, attitudes and knowledge of nurses providing PC,

## FC13 Quality of life and Symptoms

**Abstract type:** Oral

### Disease and Patient Characteristics' Associations with Quality of Life in Patients with Advanced Cancer

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**Aims:** The overall aim of palliative care is to ensure best possible quality of life (QoL). We investigated disease and patient characteristics' relationship with QoL in a large sample of patients with advanced cancer.  
**Methods:** Of 1051 patients with advanced cancer in the international European Palliative Care Research Collaborative-Computer Symptom Assessment Study (EPCRC-CSA), 455 had complete data sets (57% male). Inclusion criteria: incurable metastatic/locally advanced cancer and >18 years. Candidate variables' possible associated with QoL includes: Disease load; CRP, albumin and hemoglobin, length of survival and physical performance (Karnofsky performance scale). Patient characteristics: age, gender, pain severity (PI worst pain last 24hrs) and depression severity (PHQ9 sum score). Global QoL was measured with the EORTC-QLQ-C30 item. We used a multiple hierarchical regression model to test the effects of these characteristics on QoL.  
**Results:** Better quality of life was associated with older age, lower CRP, longer survival and higher KPS, lower pain and lower depression (see Table 1).

	M(SD)	B(SE)	$\beta$	t	p
Gender /	63.6(11.44)	-1.29(1.94)	-0.03	-0.66 /	0.508 /
Age		/0.19(0.09)	/0.09	2.20	0.028
Comorbidity	0.73(0.84)	-0.85(1.19)	-0.03	-0.72	0.475
Albumin	35.45(6.14)	-0.07(0.20)	-0.02	-0.34	0.734
Hemoglobin	11.69(1.80)	-0.40(0.59)	-0.03	-0.67	0.502
CRP	44.57(63.01)	-0.04(0.02)	-0.10	-2.29	0.023
Survival length	178.48(145.4)	0.02(0.01)	0.13	2.92	0.004
KPS	69.21(15.60)	0.25(0.07)	0.16	3.59	<0.001
Pain	3.23(2.94)	-1.38(0.34)	-0.17	-4.05	<0.001
Depression	8.00(5.29)	-1.65(0.20)	-0.36	-8.42	<0.001

[Table 1.]  
The model explained 33% of the variance in QoL, of which pain and depression uniquely



and to investigate the correlation between these factors and their professional behavior intentions. It is assumed that positive correlations will be found.

**Methods:** The correlative design sample included 214 registered nurses in community and hospital practice in the Central District. Six questionnaires were developed for the study, evaluating knowledge, attitudes, emotional coping abilities and intentional behavior in these situations. Reliability ranged from 0.72 to 0.89, measured by Cronbach's alpha and content was validated by clinical experts.

**Results:** Significant differences were found between nurses practising in various clinical areas (internal medicine, surgery, community, oncology) regarding professional background, emotional coping abilities and knowledge ( $p < 0.001$ ). However, no differences were found in intentional behavior. Higher levels of education were correlated with increased positive attitudes ( $p < 0.05$ ). There were significant correlations between level of knowledge and emotional coping abilities ( $p < 0.001$ ,  $r = 0.37$ ) and level of knowledge and professional background ( $p < 0.001$ ,  $r = 0.35$ ).

**Conclusions:** For the first time, reliable and valid assessment tools were developed to evaluate and quantify PC nursing. These tools can be utilised to measure learning outcomes in various academic and professional settings for PC education.

**Abstract number:** FC13.5

**Abstract type:** Oral

### Depression Predicts Pain Intensity: Prospective findings from the European Palliative Cancer Care Symptom Study (EPCCS)

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**Background:** Depression and pain often coexist in patients with advanced cancer. However, few studies have investigated how this relationship is influenced by pain treatment.

**Aims:** To investigate if depression status predicts self-reported pain intensity in a sample of palliative patients when controlling for analgesic treatment.

**Methods:** The EPCCS is an international prospective collection of symptoms and clinical data in 30 centres and 12 countries. 898 patients scoring  $> 3$  on a 0–10 NRS on *average pain intensity* (PI) the past 24 hours were assessed at inclusion (T1) and after 4 weeks (T2). Multiple regression analyses were used with PI at T2 as the dependent variable. *Depression*, measured by the sum score of the major depression criteria (*mood* and *anhedonia*) in the Patient Health Questionnaire-9 (range: 0–6), and *analgesic treatment* (Y/N) assessed at T1 were predictors. Age and sex were adjusted for in the analyses.

**Results:** Mean age was 65.1 (SD 12.4), 51% were women. Mean depression sum score at T1 was 2.6 (1.9). At T1 91.5% received either opioid or non-opioid analgesia. Average PI at T1 and T2 was 5.3 (1.9) and 3.8 (2.5), respectively. There were no sex differences regarding depression, PI scores or analgesic treatment. The following variables *univariately* predicted PI at T2: *Age* ( $b = -0.03$ , 95% CI  $= -0.04 - 0.01$ ,  $p < 0.01$ ), *depression* ( $b = 0.13$ , (0.03–0.24),  $p < 0.05$ ) and *analgesic treatment* ( $b = 1.36$ , (0.71–2.0),  $p < 0.01$ ). In a multivariate regression model, all three variables remained significant predictors of PI at T2: *age* ( $b = -0.03$ , (-0.04–0.01),  $p < 0.01$ ), *depression* ( $b = 0.11$ , 0.001–0.22),  $p < 0.05$ ) and *analgesic treatment* ( $b = 1.44$ , (0.80–2.08),  $p < 0.01$ ).

**Conclusions:** Baseline depression exerts an independent effect on pain intensity assessed after 4 weeks irrespective of analgesic treatment and controlled for age and sex. This suggests that mood should be routinely assessed together with pain in palliative care patients.

**Abstract number:** FC13.6

**Abstract type:** Oral

### Risky Recruitment: Feasibility of Recruiting Patients to a Cancer Associated Thrombosis Clinical Trial - Insights from an Embedded Qualitative Study

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**Background:** Cancer associated thrombosis (CAT) clinical guidelines advise six months' low molecular weight heparin (LMWH), but beyond six months there is a lack of evidence. The ALICAT (Anticoagulation Length in Cancer Associated Thrombosis) randomised controlled trial (RCT) aimed to establish the feasibility of recruiting patients to compare: LMWH for a further six months (intervention) with ceasing LMWH at six months (control). A qualitative study was embedded in the RCT, a novel approach in palliative care research.

**Aim:** The embedded study aimed to explore patients' and clinicians' perspectives of the ALICAT RCT. This paper presents attitudes to recruitment reported by clinicians and patients who declined randomisation.

**Methods:** Focus groups ( $n = 3$ ) were conducted with oncology, haematology and primary care clinicians. Patients ( $n = 8$ ) with CAT who declined randomisation into the RCT were interviewed. Data were analysed using the Framework approach.

**Results:** Patients declined randomisation due to perceived risk of entering the RCT, ceasing LMWH and experiencing further thrombosis. Dislike of injecting LMWH (and thus concern they would be randomised to the intervention) and feeling too unwell to attend clinic were also reasons that patients declined RCT participation.

Clinicians agreed that for some patients the risk of further thrombosis was too high and they would thus be reluctant to introduce them to the ALICAT RCT. They were also concerned about balancing the risk of thrombosis and haemorrhage.

**Conclusion:** These attitudes to risk indicate participants are not confident that the RCT is equitable. Interestingly patients are motivated by thrombosis risk, while clinicians are concerned by haemorrhage. Despite the need for evidence guiding ongoing CAT treatment, this study suggests reluctance towards a RCT comparing continuing or ceasing LMWH beyond six months. There is thus a need to design and pilot further research to guide CAT management beyond six months.

**Funding:** NIHR HTA

## FC14

### Communication and education

**Abstract number:** FC14.1

**Abstract type:** Oral

### What Happens after Breaking Bad News: The Process of Sharing A Cancer Diagnosis with Adult Family Members and Friends

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**Background:** Worldwide over 1.6 million people are diagnosed with lung cancer each year. Extensive research exists on how such news is broken by physicians to patients. Little is known about the subsequent stage, when patients go home and share that news with family members and friends, although this is a difficult experience for patients.

**Aim:** To understand the experience of sharing news of a lung cancer diagnosis with wider family members and friends (adults) to inform a supportive intervention to prepare patients for sharing bad news.

**Methods:** Qualitative interviews with 20 patients with lung cancer and 17 family members/friends present at diagnosis-giving consultations to explore experiences of receiving a cancer diagnosis and how news was then shared with wider family/friends. A time line was created with participants to map the timing of news sharing. Data were digitally recorded, transcribed verbatim and a thematic framework analysis conducted.

**Results:** There were three key findings.

- 1) Patients received a series of 'news events' from clinicians along their cancer trajectory: it was not a discrete event. Sharing that news also happened over time, at any point along the trajectory: again, it was a process, not a discrete event.
- 2) Timing of sharing bad news was very individual. Participants reported that they needed to prepare themselves for sharing the news and needed to feel ready to share.
- 3) Regardless of when news was shared it had consequences in terms of the reactions of those told. Illustrative timelines of processes of early and later sharing of bad news will be presented.

**Conclusion:** Understanding sharing bad news as a process which happened over time was a significant finding for the design and delivery of a supportive intervention. Preparing patients to share bad news of a lung cancer diagnosis, which often presents at an advanced stage, is highly relevant for palliative care.

**Funder:** Dimpleby Cancer Care

**Abstract number:** FC14.2

**Abstract type:** Oral

### Pushing up Daises, Slipping Away or Dying – A Qualitative Study on the Expressions of Death and Dying among Family Members of Palliative Patients

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**Background:** Good communication is a core activity in palliative care. To be able to adapt end-of-life discussions to the individual, it seems important to study how family members (FMs) actually communicate about death and dying.

**Aims:** To examine FMs' use of expressions when writing about death and dying.

**Methods:** This study was based on a secondary analysis of data collected in a cross-sectional study of FMs' experiences of powerlessness during palliative home care. The responses from 233 FMs to open-ended questions were analysed with qualitative content analysis.

**Results:** The analysis resulted in three themes of expressions of death and dying. 1) *Explicit expressions* were e.g. 'death', 'dying' and 'to decease', and they were often used in rational descriptions without apparent emotional turmoil, often describing an acceptance of what had happened. 2) *Metaphorical expressions* were focusing on different aspects of death such as loss, gradual deterioration, a calm rest, e.g. 'he went to sleep'. 3) Those using *implicit expressions* avoided distinct expressions aiming at death or dying, and instead used very diffuse terms or even skipped writing an expression at all, just leaving a blank space in the text. Those using an implicit language often described great personal psychological suffering.

The FMs described discontentment arising from bad communication with health care staff about death and dying. Some had experienced that health care staff had been too direct and explicit about death and dying, which was perceived as offensive and distressing. However, others experienced that communication about death and dying had been too indirect and implicit, and therefore difficult to understand, which had made the patient and family unable to comprehend and plan according to the situation, which in hindsight was saddening.

**Conclusion:** Important aspects of how FMs communicate about death and dying were identified and these have implications for clinical practice and future research.

Abstract number: FC14.3  
Abstract type: Oral

## Preparing Family Caregivers of Nursing Home Residents with Dementia for the End of Life: Development of a Question Prompt Sheet

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**Background:** Research examining family members' perceptions and satisfaction with end-of-life care provided in nursing homes demonstrates that family caregivers have significant unmet information needs and often feel unprepared for the death of the resident. Though they often have questions about death and dying as their relative's illness progresses, research suggests that not knowing what to ask, worries about being perceived as ignorant, and feeling overwhelmed pose barriers to families talking with clinicians.

**Aims:** The goal of this study was to develop an empirically derived communication tool aimed at facilitating dialogue between family caregivers and care providers concerning the end-of-life care of nursing home residents with dementia.

**Methods:** Using qualitative research methods, a convenience sample of bereaved family members of residents with dementia (n=17), health care providers in gerontology (n=26) and palliative care (n=6) were interviewed regarding their experience, knowledge, and care of residents with dementia. Coding of interview transcripts focused on generation of themes and questions that were important to include on a question prompt sheet (QPS) about end-of-life care for residents with dementia. The items generated were reviewed by the participants for clarity, relevance, and importance and vetted by an international advisory panel.

**Results:** Analysis identified 6 thematic areas and 31 questions were developed to cover the information respondents deemed critical for families to have conversations with care providers about, in order to understand quality care along the dementia trajectory.

**Conclusion / Discussion:** The QPS-AD aims to improve communication between families and care providers around the progression of dementia in the context of the nursing home; a prerequisite to improving the provision of palliative care in this setting. Funding received by the Canadian Institutes of Health Research and Manitoba Health Research Council.

Abstract number: FC14.4  
Abstract type: Oral

## Using a Novel Approach Training in End of Life Care: Evaluation of a Multidisciplinary (MDT) Simulation Based Training Course

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**Background:** Care of the dying requires healthcare professionals to have substantial technical knowledge, clinical skill and excellent communication skills.

**Aims:** To develop and pilot an MDT simulation course focused on care in the last hours or days of life and to evaluate the impact of the training.

**Methods:** The bespoke course consisted of an e-learning component & one study day focusing on 4 scenarios simulating the last days of life of a patient and family in hospital. The course was piloted on 2 occasions in one hospital. The evaluation included pre and post course questionnaires & a thematic analysis of post course focus group interviews.

**Results:** 12 participants completed the and 4 nursing assistants (NAs): median age 33 years, 67% female. 11 participated in focus groups immediately following the training. Participants were overwhelmingly positive about the course, valuing the realism, small group size and MDT nature of the training. Feedback and the opportunity for reflection including the use of video recording were also highly valued. The participants were fairly knowledgeable and held generally positive perceptions of caring for dying patients prior to the training. The greatest shift pre to post training was seen in the reduction of participants level of perceived helplessness when caring for dying patients. Confidence in all three domains (communication, management of the Patient, MDT working) was relatively high (around 60%) pre-training, particularly for MDT working. It rose immediately post training (T2) to between 70–80% in all domains but especially with regard to communication with the family and the provision of and referral for spiritual care.

**Conclusions:** Though the sample for this evaluation was very small, the course was universally valued by participants. Findings from the evaluation have been used to refine the course content and delivery and further courses are planned. Work is also underway to refine the evaluation tools.

Abstract number: FC14.5  
Abstract type: Oral

## A Change Is Needed in the Understanding of Anticipatory Grief: A Systematic Review of Existing Studies

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**Background:** Family caregivers of terminally ill cancer patients may experience anticipatory grief before the actual loss of the patient. Anticipatory grief has formerly been thought to improve bereavement outcome, but recent studies have indicated that it may, in fact, have a negative impact.

**Aims:** The aim was to investigate

- 1) the definitions and quantitative measurements of anticipatory grief and
- 2) the effect of anticipatory grief on bereavement outcome.

**Method:** The study used a systematic approach to literature reviews in line with the PRISMA statement. Databases were searched for publications from 1990 to 2013. Studies on adult caregivers of adult cancer patients with advanced illness were included, if a quantitative measurement of anticipatory grief had been used. Definitions, measurements and results

related to anticipatory grief were identified and key points were extracted.

**Results:** In the eleven included studies, anticipatory grief was described as either 'a reaction', 'a feeling of grief or stress' or 'complicated pre-loss grief' occurring before death. Therefore, anticipatory grief can be defined as 'pre-loss grief'. Anticipatory grief symptoms of caregivers were measured on seven different scales in the eleven included studies. In four out of six included follow-up studies, the presence of anticipatory grief was associated with worsened bereavement outcomes e.g. depressive symptoms or complicated grief, while two studies found no association.

**Conclusions:** Anticipatory grief was reported as pre-loss grief and was associated with worsened bereavement outcome. However, only few eligible studies had been carried out, and included measurements were inconsistent. The concept of anticipatory grief must thus be questioned, and the term 'pre-loss grief' may apply better to caregivers' grief before the death of the patient. Targeted support should be directed to caregivers experiencing pre-loss grief, as this is associated with worsened bereavement outcomes.

Abstract number: FC14.6  
Abstract type: Oral

## Professional Communication about Advance Care Planning in Community Care Settings

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**Aim:** This paper reports findings from a UK study of communication about advance care planning (ACP) in community care. ACP is a key component of current policy to improve the experience of death and dying by enabling patients to consider options and preferences for future care. Limited evidence indicates that professionals and patients find such discussions difficult and that they are uncommon.

**Methods:** Qualitative study involving

- 1) longitudinal case studies of patient, carer and professional triads and
- 2) interviews with health professionals.

Thematic analysis of data using constant comparative method.

**Results:** Professionals reported communication about ACP to be difficult and tended to avoid it. They cautiously searched for, and laid down, cues that patients were 'ready' and receptive to discussion, expecting many patients to reject this invitation. Tentative approaches were couched in vague and euphemistic language. When they occurred, ACP discussions tended to focus on documentation of a few key decisions, such as resuscitation and place of death, rather than wider discussion of patients' goals and values. ACP tended to be reactive, rather than anticipatory, and prompted by the recognition that death was imminent. Discussion focused on engendering a sense of 'realism' rather than promoting precedent autonomy.

**Conclusions:** Vague language and gentle cues enable patients to respond selectively to offers of ACP discussion, but risk perpetuating evasion and misunderstanding. When ACP occurs, professional agendas and assumptions can impose a subtle pressure on patients and carers to conform to normative expectations about the best and appropriate way to die. ACP discussions were often challenging for patients and professionals, and frequently lacked salience. The distance between ACP policy and its translation into practice prompts reflection about its purpose, based on greater understanding of patient perspectives and priorities for end of life care.

## FC15 Healthcare evaluation and needs

Abstract number: FC15.1  
Abstract type: Oral

## Exploratory Analyses of the Danish Palliative Care Trial (DanPaCT), a Randomised Trial of Early Specialised Palliative Care (SPC) versus Usual Care in Cancer Patients

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**Background:** Patients with metastatic cancer often experience considerable symptoms and problems.

**Aim:** To investigate whether early SPC reduces symptoms and problems and increases satisfaction with the health care system (explorative outcomes).

**Methods:** The trial is a multicentre, parallel-group, superiority clinical trial with 1:1 randomisation conducted at six SPC centres. Consecutive patients with metastatic cancer were included if they had symptoms or problems measured with the EORTC QLQ-C30 questionnaire that exceeded a predefined threshold. In total, there were one primary and eight secondary outcomes (reported elsewhere). Exploratory outcomes were the changes in the EORTC QLQ-C30 scales cognitive function, social function, quality of life, fatigue, sleeplessness, constipation, diarrhoea, and financial difficulties; the Hospital Anxiety and Depression scales anxiety and depression; and the FAMCARE p-16 single items measuring

satisfaction with the health care system, and one additional item measuring overall satisfaction, to the 3- and 8-weeks follow-up measured as area under the curve. All analyses were made as complete case analyses. Relevant sensitivity analyses will be reported at the conference.

**Results:** Totally 145 were randomised to early SPC versus 152 to standard care only. Early SPC had no significant effects on any of the symptoms or problems. Of the 17 items addressing satisfaction/overall satisfaction with the help received from the health care system had a difference favoring early SPC of 9 points (0–100 scale) ( $p=0.0006$ ) and three other items were significant with  $p<0.05$  (all favoring the SPC group). These were doctors' attention to description of symptoms, information given about how to manage pain, and the way family was included in decisions.

**Conclusion/ discussion:** The explorative outcomes showed no effect on symptoms and problems but a tendency for patients in the SPC group to be more satisfied with the health care received.

**Abstract number:** FC15.2

**Abstract type:** Oral

### Early Palliative Care for Patients with Metastatic Lung Cancer Receiving Chemotherapy: A Feasibility Study of a Nurse-led Screening Program

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**Background:** Providing early palliative care (EPC) is important, but it is unclear how this should be provided.

**Aims:** This study aimed to assess the feasibility of a nurse-led screening program for EPC intervention.

**Methods:** Patients with metastatic lung cancer undergoing first-line platinum-based chemotherapy (CTx) in an inpatient setting were eligible. The intervention was to promote receiving EPC using a brief screening questionnaire, followed by a comprehensive program which involved certified nurses' visiting, identifying problems, and arranging intervention of each profession if necessary. The primary endpoint was the completion rate of the assessment questionnaires after the second course of the first-line CTx (T2). The secondary endpoints included changes in score of the Functional Assessment of Cancer Therapy-Lung (FACT-L), the rate of depression and anxiety assessed using Patient Health Questionnaire-9 and Hospital Anxiety and Depression Scale, and the contents of the EPC provided.

**Results:** From August 2012 to March 2014, 50 patients were enrolled. The median age was 66 years (range, 40–78), and 84% were men. Thirty-eight patients had stage IV non-small cell lung carcinoma and 12 had extensive disease small-cell lung carcinoma. The completion rate was 70% (95% CI 56.0–81.0). The mean duration between baseline and T2 was 51.2 days. The reasons for non-completion were not receiving platinum-based CTx ( $n=2$ ), switching to outpatient CTx ( $n=2$ ), changing to second-line CTx ( $n=2$ ), discontinuation of CTx ( $n=3$ ), poor physical condition ( $n=2$ ), and unwillingness ( $n=4$ ). Forty-four patients received specialised palliative care. The FACT-L scale and the rates of depression and anxiety tended to improve from baseline.

	Baseline ( $n=50$ )	T2 ( $n=35$ )	Change from baseline (95% CI)	P value
FACT-L	86.0	94.9	8.9	0.057
scale	$\pm 18.1$	$\pm 18.2$	(1.1 to 13.1)	

[Change in quality of life]

**Conclusion:** This EPC intervention is feasible and potentially useful. Our results justified a further randomised control trial.

**Abstract number:** FC15.3

**Abstract type:** Oral

### CaNoPy: A Study of the Care Needs of Patients with Idiopathic Pulmonary Fibrosis and their Carers

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**Background:** Idiopathic pulmonary fibrosis (IPF) is a chronic interstitial lung disease with varying clinical course, no proven treatment and median three year survival. Symptom burden is high and quality of life (QoL) poor. Guidelines promote patient-centred approaches, emphasising supportive and palliative care interventions. However little is known of patient and carer experiences in order to guide care pathways.

**Aims:** To identify changes in individuals' and carers' perceived palliative and supportive care needs over the course of IPF to inform future service interventions and delivery.

**Methods:** Multi-centre mixed-methods study across four stages of the IPF trajectory. Interpretative Phenomenological Analysis was used to analyse eight sets of semi-structured interviews with patients (27) and paired carers (21) in four groups ( $n=48$ ). Patients also completed validated questionnaires exploring QoL and symptoms.

**Results:** Patients and carers outlined key transition points where IPF made significant impact, representing triggers for focused palliation. These related to diagnosis, changes in health status e.g. symptom progression, and introduction of oxygen, and loss of normality. Participants perceived a lack of relevance of IPF clinic assessments to their lived experience, emphasising the burden of living with prognostic uncertainty and the active role of carers. Disparities in information needs and coping styles over time highlight the need for individualised patient and carer interventions.

**Conclusions:** CaNoPy is the first study to explore perceived care needs over the IPF trajectory and to examine carer perception in detail. Key triggers for palliative interventions relate to roles, function and life events rather than to objective clinic based assessments, necessitating a shift in focus of clinical encounters. Study outcomes will inform training and practice of IPF multidisciplinary teams, including timing of access to palliative care.

**Abstract number:** FC15.4

**Abstract type:** Oral

### A Comparative Observational Study of the AMBER Care Bundle: Care Experiences of Clinical Uncertainty and Deterioration, in the Face of Limited Reversibility

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**Background:** Clinical uncertainty is emotionally challenging for patients and carers, and creates additional pressures for clinicians in acute hospitals. The AMBER care bundle was designed in the UK to improve care for patients identified as clinically unstable, deteriorating, with limited reversibility, and at risk of dying in the next 1-2 months.

**Aims:** To explore whether there were differences in care experience between patients who were cared for supported by the AMBER care bundle and those receiving standard care.

**Methods:** Comparative observational mixed-methods study using semi-structured qualitative interviews, and a followback survey (QUALY-CARE). Interviews with 23 patients and carers (12 supported by AMBER care bundle, 11 standard care) were analysed using thematic analysis; surveys of 95 bereaved carers (59 AMBER care bundle, 36 standard care) were analysed using t-tests and  $\chi^2$  tests, focusing on questions about communication, awareness of illness, and length of hospital stay. The interview and survey data were integrated at the point of analysis, in a convergent design, interrogating the data around common key themes.

**Results:** The AMBER care bundle was associated with increased frequency of discussions about prognosis between clinicians and patients ( $\chi^2=4.09$ ,  $p=0.04$ ), higher awareness of their prognosis by patients ( $\chi^2=4.29$ ,  $p=0.04$ ), but lower clarity in the information received about their condition ( $\chi^2=6.26$ ,  $p=0.04$ ). The consistency and quality of communication was not different between the two groups, but those supported by the AMBER care bundle described more unresolved concerns about caring for someone at home.

**Conclusion:** Awareness of prognosis appears to be higher in patients supported by the AMBER care bundle, but in this small study this was not translated into higher quality communication, and information was judged less easy to understand. Adequately powered comparative evaluation is urgently needed.

**Funding:** Guy's and St Thomas' Charity, UK.

**Abstract number:** FC15.5

**Abstract type:** Oral

### Access to Palliative Care of Homeless People: Perceived Barriers and Facilitators from Different Viewpoints

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**Background:** Homeless people may have various physical, psychosocial and psychiatric problems, including substance abuse. They have a shorter life-expectancy (< 20 yrs) in comparison with the general population and often avoid help for the problems mentioned. They relatively often suffer from progressive diseases like COPD, chronic heart failure and lung cancer. Little is known about how palliative care for this target group is organized and can be improved.

**Aim:** The aim is to describe the characteristics of palliative care for homeless people in the Netherlands and what barriers and facilitators exist for palliative care from the perspectives of the patients, their relatives and professionals.

**Methods:** In this qualitative study fifteen cases of homeless people needing palliative care are intensively studied. For each case we interview on average 3 people, including patients, relatives/friends, doctors, nurses and social workers. The interviews are transcribed verbatim and analysed inductively. Interviews are held in 2014 and 2015.

**Results:** Preliminary data show that different organisations and professionals are involved with homeless people. It is difficult to maintain long-lasting relationships with the patients. Their social network is often not stable and unable to give sufficient support. Mental health professionals generally feel inadequately trained to provide good palliative care. On the other hand, professionals in palliative care feel inadequately trained in deal with psychiatric problems and challenging behavior.

**Conclusion:** As far as we know this is one of first studies describing palliative care practices for homeless people. Cooperation between palliative care professionals and mental health professionals, who have much experience in supporting this target group, is needed to improve care for homeless people at the end of life and to realize better access to palliative care.



Abstract number: FC15.6  
Abstract type: Oral

## Which Everyday Activity Problems Do People with Advanced Cancer Living at Home Prioritise - And Can Types of Activity Problems Be Predicted?

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**Background:** Worldwide people live longer with advanced cancer, and research shows that many have problems with everyday activities. Yet it is not known which types of activities they have problems with and prioritise. When planning interventions it would be useful to be able to predict which types of activity problems subgroups have.

**Aims:** To investigate which everyday activity problems people with advanced cancer have and prioritise, and to identify predictors for different types of activity problems.

**Methods:** In the cross-sectional part of 'The Cancer Home Life Project' 164 adults diagnosed with advanced cancer (median age 68 years, 52% men, different cancer diagnoses) were enrolled consecutively from two hospitals. Demographic and health data were collected in addition to data on prioritised activity problems using 'The Individually Prioritised Problems Analysis' (IPPA). Activity problems were grouped according to the ICF. Associations between activity problems and possible predictors (age, gender, living situation, cancer diagnosis, and symptoms) were accomplished using regression analyses of variables identified in bivariate analyses.  $P \leq 0.05$  was considered statistically significant.

**Results:** The most frequently prioritised activity problems concerned: move around; transportation; prepare meals and do housework; maintain dwelling and vehicle; take care of plants; maintain social relationships; employment; sports and training, hobbies; socialising and holidays. Out of 120 tested associations, 23 were statistically significant in the bivariate analyses and 10 in the regression analyses with no trends in prediction of subgroups' prioritised activity problems.

**Conclusion:** The prioritised activity problems mostly concerned fulfilment of social roles, maintaining everyday life, and enjoying leisure activities. The fact that it was only possible to predict few prioritised activities shows that these are individual, and interventions should be based on dialogue.

**Abstract number:** FC16.1

FC16

International developments and research

Abstract type: Oral

## Recommendations for Political Decision Makers Based on Results from a Pre-test on the Use of Quality Indicators across 4 Settings in 5 Countries

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**Background and aims:** The overall aim of the IMPACT study is to develop tailored strategies for the implementation of quality indicators (QIs) to improve the organisation of palliative cancer and dementia care in Europe. For this purpose, the literature was systematically searched for organisational QIs in palliative care (PC). A set of 23 QIs was derived using a RAND Delphi. A pre-test on the use of this QI set was conducted among 40 services across 5 European countries (ENG, D, IT, NL, NO). The aim of this part of the study is to derive recommendations for political decision makers in order to facilitate political support for the implementation of QIs.

**Methods:** Quantitative data from the questionnaire with the consented and operationalised QIs were searched for measurements of low performance. Qualitative data from the participating services (field notes, transcripts of audiotaped sessions, categorisations of audiotaped sessions and interviews) were searched for aspects that address preconditions for better performance.

**Results:** Six most important recommendations for political decision makers emerged and will be presented along with suggestions for steps to be taken. These include

- Promotion of
- 24/7 availability of specialised PC teams in all relevant settings
- Electronic patient files that are accessible 24/7 for professional carers in charge
- The use of regular assessment of pain and other symptoms in all settings caring for patients in need PC
- Multi-professional team meetings to be held on a weekly basis in all settings;
- The necessity of family (and patient) satisfaction assessment; and
- Accredited training for all professions involved in the delivery of PC.

**Conclusion:** Data from the pre-test and discussions with the participating services in this study on the implementation of QIs strongly suggest that there are barriers which cannot be overcome without support from political decision makers.

**Funding:** EU FP7/2007-2013; grant agreement 258883

Abstract number: FC16.2  
Abstract type: Oral

## Palliative Care Integrated into the Policy Architecture, Health Infrastructure, Service Delivery and Culture of a Nation: Defining Potential Models through Lessons from Four Countries in Sub-Saharan Africa

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**Background:** Islands of excellence of palliative care provision exist in many African countries. There is limited evidence on the process and the effects of what full integration into national health systems could deliver.

**Aims:** To build models of integrated hospital to community care based on the vision, workforce capacity, community need and services, and to capture their evolution and impact.

**Methods:** A 3 year (2012–2015) THET funded multi-country partnership project on Strengthening and Integrating Palliative Care into National Health Systems led by the University of Edinburgh, the African Palliative Care Association, Makerere University, National Palliative Care Associations, working with national Ministries of Health and in-country organisations developed 12 models of integration in 12 hospitals, 3 each in Rwanda, Kenya, Uganda and Zambia. Baseline data was married with hospital, community vision and national strategies to build an investment plan focused on basic training for different cadres of health workers, specialist training, clinical and pharmacy protocol and service development, community awareness raising, referral pathway processes, and advocacy. Training was followed by a south-south and north-south mentoring programme.

**Results:** 12 hospitals have developed models of care ranging from inpatient bedded units, link nurse programme, shared hospice and hospital programmes and outpatient services. 1035 staff have been trained at various levels, 12 palliative care protocols have been adapted into national health systems, national strategies have been adapted, and morphine availability has increased. Staff have increased confidence to believe in palliative care as a service, as a system and as an approach to care that honours life and dying.

**Conclusion:** Palliative care integration into national health systems can only be achieved with integration of the training, management, and infrastructure needs of a hospital working with, in and through its community.

Abstract number: FC16.3  
Abstract type: Oral

## Systematic Review of Foci, Designs and Methods of Palliative Care Research Conducted in Sweden between 2007 and 2012

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**Background:** In order to guide further development of palliative care research, national reviews regarding characteristics of national PC research is suggested. In Sweden, a previous review of national palliative care from the 1970s to 2006 provided a useful source for comparison with research conducted during the subsequent six years.

**Aim:** To systematically examine palliative care research from Sweden between 2007 and 2012, with special attention to research foci, designs and methods.

**Methods:** A systematic review was undertaken. The databases Academic Search Elite, Age Line, Ahmed, Cinahl, PsychInfo, Pub Med, Scopus, Soc abstracts, Web of Science and Libris were reviewed for Swedish palliative care research studies published from 2007 to 2012, applying the same search criteria as used in the previous review.

**Results:** A total of 263 papers met the inclusion criteria, indicating an increased volume of research compared to the 133 articles identified in the previous review. Common study foci were symptom assessment and management, experiences of illness, and care planning. Targeting non-cancer specific populations and utilisation of population-based register studies were identified as new features. There was continued domination of cross-sectional, qualitative and mono-disciplinary studies, not including ethnic minority groups, non-verbally communicable people, or children under 18 years of age.

**Conclusion:** Palliative care research has increased in Sweden, from 2007 to 2012 compared to during the 1970s to 2006, and there is an increased trend for research of non-cancer specific populations. A domination of qualitative approaches and small, cross-sectional studies with few interventions is still characteristic. Still more strategies are needed to expand the knowledge development of palliative care to respond to demographical, epidemiological, therapeutic and health care structure changes.

**Abstract number:** FC16.4  
**Abstract type:** Oral

### Effects of eHealth for Patients and Informal Caregivers Confronted with Cancer: A Meta-review

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**Background:** In current health care, eHealth is considered as a potentially effective mean for providing information and support. eHealth can be defined as 'information provision about illness or health care and/or support for patients and/or informal caregivers, using the computer or related technologies'. Several systematic reviews concerning effects of eHealth interventions for cancer patients are already published.

**Aim:** To synthesise evidence from previous systematic reviews on the effects of eHealth interventions in oncology care, and to look whether these interventions and effects also concern patients and informal caregivers in the palliative phase of cancer.

**Methods:** A systematic meta-review (a systematic review of reviews) was conducted on effects of eHealth interventions targeting cancer patients and/or informal caregivers. Searches were done in PubMed, Embase, CINAHL, PsycINFO and Cochrane Library. The reference selection and methodological quality assessment were done by two reviewers independently.

**Results:** Ten systematic reviews were included. Based on a synthesis of the information from these reviews, moderate evidence was found for the efficacy of eHealth regarding support, knowledge levels and information competence of cancer patients. Evidence was inconclusive for outcomes related to wellbeing, depression, quality of life, decision making and health care participation. None of the reviews included studies targeting eHealth for palliative care patients and/or their informal caregivers.

**Conclusion:** There is (moderate) evidence that eHealth interventions are effective in providing support and in increasing information competence of patients. There is an urgent need for research into the effects of eHealth in the palliative phase of cancer.

**Funding:** ZonMw, The Netherlands Organisation for Health Research and Development.

**Abstract number:** FC16.5  
**Abstract type:** Oral

### End-of-Life Chemotherapy in South Western Finland during 2003-2014: A Population-based Single-centre Study

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**Background:** In the treatment of end-of-life patients, palliative symptom control should be preferred over aggressive anti-cancer treatments. However, terminally ill cancer patients are often over treated with chemotherapy, which can cause additional suffering and weaken the quality of life. We assessed the use of chemotherapy for cancer patients in the last year of life in a population of c. 450,000.

**Methods:** All cancer patients treated with chemotherapy and deceased in the University Hospital District in 2003–2014 were included in the population-based single-centre study. All cancer types were included. ICD-10 diagnoses C00–C97, age at death, date of death, and chemotherapies were gathered from the electronic medical records. The use of chemotherapy was assessed one year, six months, three months, two months and one month before death in regard to patients' age and the type of cancer.

**Results:** Among the 13 855 deceased cancer patients, 4083 (~30 %) patients received chemotherapy and ~80 % (3289) of them, during the last year of life. Chemotherapy was received six months, three months, two months and one month before death by 64%, 40%, 24% and 8% of all the patients, respectively. Median age at death was 67.1 years. Median time between last chemotherapy and death was 122 days. No significant changes were observed across the follow-up years. The time was dependent on patients' age. Three months before death 56% of patients below 50 years of age received chemotherapy while in age groups 50–70, 70–80 and >80 years of age, the corresponding percentages were 44%, 33%, and 19%, respectively. The differences in each pairwise comparison were statistically significant (p-value < 0.01). The patients above 80 years of age were treated below the average.

**Conclusions:** In the present 10 year study, aggressiveness of late chemotherapy treatments did not increase. On the contrary, time from treatment to death tended to increase in the age group >80 years. Cancer type specific differences found will be presented.

**Abstract number:** FC16.6  
**Abstract type:** Oral

### Strong Country-variation in Nursing Home as a Place of Death for Older People. A Study in Thirteen Countries across Four Continents Using Death Certificate Data

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**Background:** With the ageing of populations, more evidence is needed about where older people die. Identifying how patterns of place of death change with increasing age provides information on where the monitoring and safeguarding of the quality of end-of-life care for older people is priority. Cross-national research allows examination of transnational processes like place of death across diverse contexts, providing information on policies and on health and social care systems.

**Aims:** To study place of death of older people in 13 countries; to evaluate if nursing home death rates increase with increasing old age; to identify factors associated with nursing home deaths in this older population.

**Methods:** Death certificate data for the full population of deaths in 14 countries were collected and pooled into one database. Descriptive and multivariable binary logistic regression analyses were performed to evaluate place of death patterns across four age groups: 80–84, 85–89, 90–94, ≥95. Three models of analysis were conducted to explain determinant factors of nursing home deaths among the oldest population.

**Results:** Home deaths among those ≥80 varied from 9.3% (Canada) to 62.8% (Mexico); nursing home deaths varied from 2.9% (Korea) to 52.8% (Netherlands). The chances of a hospital death strongly decreased and the chances of a nursing home death strongly increased with more advanced older age. This age-effect was particularly strong in Wales. Determinants of nursing home deaths were older age, being female, Alzheimer disease as cause of death and higher availability of nursing home beds in the region. These variables only partially explain country variations.

**Conclusions:** Large cross-national differences were found concerning place of death in the oldest population. In all countries, nursing home deaths strongly increased with more advanced older age, highlighting the growing relevance of promoting palliative care in these settings in all ageing societies.

**Abstract number:** FC17.1

## FC17 Symptom management

**Abstract type:** Oral

### Using Palliative Care Quality Network Core Data to Drive Quality Improvement in Pain

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**Background:** Standardised data collection and outcome assessment in palliative care can define best practices and promote quality improvement (QI).

**Aim:** Describe how the Palliative Care Quality Network (PCQN) dataset drives QI in pain management.

**Methods:** The PCQN core dataset consists of 23 data elements including demographics, processes of care and patient outcomes. The database generates automated reports with comparison across sites. We analysed PCQN data on pain to drive QI.

**Results:** To date, 12 sites have submitted data on 7080 patients. Of the 3120 patients who could rate pain, 30% (n=923) had moderate/severe pain at first assessment. Pain management was a reason for consultation for only 54% (n=494) of patients with moderate/severe pain. For these patients, the mean time from admission to PCS consultation request was shorter than for those not referred for pain management (4 vs. 5 days; p=0.01).

Overall, 65% (162/250) of patients with moderate/severe pain reported an improvement by the second assessment within 72 hours. Younger patients and those with moderate or severe pain, cancer, and improved anxiety were more likely to report improved pain. In multivariate analysis, age and diagnosis were no longer associated with improvement. Across PC teams, the percentage of patients with improved pain ranged from 60–80%. The best performer saw patients sooner after admission (4 days) compared to the worst performer (7 days).

**Conclusions:** Standardised data collection by PCQN sites informs QI initiatives and identifies targets to improve care. Only half of patients with moderate/severe pain had pain management identified as a reason for consultation. Screening patients for pain at admission may improve care. PCQN data show that age and diagnosis were not associated with improved pain and need not be specific targets for QI efforts. There is variation in performance across sites. Understanding structure and processes of best performers could enhance care at other sites.

**Abstract number:** FC17.2

**Abstract type:** Oral

### Blinded Patient Preference of Morphine in Chronic Refractory Breathlessness - More Than Meets the Eye

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**Background:** Little attention has been given to patients' preference for morphine therapy in the setting of chronic refractory breathlessness. However, this is one important factor in considering a longer term therapy.

**Aims:** To explore blinded patient preference of morphine compared to placebo in the setting of chronic refractory breathlessness and to establish predictors of preference.

**Methods:** This was an aggregation of data from three randomised, double-blind, cross-over studies of morphine vs placebo (4 days each) in the setting of chronic refractory breathlessness. Blinded preferences were chosen at the end of the study. A multivariable regression model was used to establish patient predictors of preference.

**Results:** Sixty-five participants provided sufficient data (60 males, median age 74 years, heart failure 55%, median ECOG 2). Forty-two percent of participants preferred morphine (32.3% placebo and 24.6% no preference). There was a strong correlation between morphine preference and young age (p<0.001). There was also an inverse correlation between morphine preference and sedation (p<0.05). An inverse correlation between nausea and morphine preference was seen in the univariable model only (p<0.05). No correlation was seen between morphine preference and breathlessness intensity, either at baseline or change from baseline.

**Conclusion:** Participants preferred morphine over placebo for the relief of chronic refractory



breathlessness. Younger age is associated with preference. Absence of nausea and sedation also appear to influence choice. Preference was not correlated with quantitative improvement of breathlessness.

**Abstract number:** FC17.3  
**Abstract type:** Oral

## Effects of Melatonin on Physical Fatigue and Other Symptoms in Patients with Advanced Cancer in Palliative Care: A Double-blind Placebo-controlled Crossover Trial

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**Background:** Patients with advanced cancer often suffer from fatigue, pain, depression and other symptoms that negatively impact quality of life. Previous research suggests that melatonin could have a potential in treating these symptoms.  
**Aims:** To investigate the effect of melatonin on fatigue and other symptoms in patients with advanced cancer.  
**Methods:** Patients who were at least 18 years, had a histologically confirmed stage IV cancer and who were at least quite a bit tired were recruited from our palliative care unit. This was a double-blind, randomised, placebo-controlled crossover trial. Patients received one week of 20 mg melatonin or a placebo orally each night, before crossing over and receiving the opposite treatment for one week. Between the two periods, a wash out period of two days was implemented. Outcomes were measured using the Multidimensional Fatigue Inventory (MFI-20) and The European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire, palliative version (EORTC QLQ-C15-PAL). Physical fatigue from MFI-20 was the primary outcome. The primary analysis was a complete complier analysis, i.e. only including patients who had consumed at least 5 capsules pr. week and who had answered the MFI-20 on day 1, 7, 10 and 17. Sensitivity analyses using multiple imputations including all randomised patients and all patients completing the intervention were conducted.  
**Results:** 72 patients were randomised. 50 patients completed the intervention. 44 were complete compliers. No significant differences between placebo and melatonin periods were found for the primary outcome physical fatigue (mean difference=2.8 on 0–100 scale,  $p=0.56$ ) or for any secondary or explorative outcomes. This finding was supported in the sensitivity analyses.  
**Conclusion:** Oral melatonin 20 mg for one week did not improve fatigue or other symptoms in patients with advanced cancer.

**Abstract number:** FC17.4  
**Abstract type:** Oral

## Late Breaking Abstract: Cancer Cachexia Classification in a Large Longitudinal Patient Cohort

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**Background:** Cachexia is a devastating syndrome in cancer leading to weight loss, loss of function and death. A three-stage cachexia classification has been proposed: pre-cachexia (PC), cachexia (C) and refractory cachexia (RC). This classification system has not been fully assessed in a clinical setting so its applicability is unknown. Also biomarkers of PC are unknown. Identification of patients at risk of cachexia would enable early treatment and thus increase the probability of effect.  
**Aim:** The primary aim is to describe the prevalence of the stages of cachexia, patients' transition from stage to stage, and survival of patients by stage. A secondary aim is to identify biomarkers indicating risk of cachexia development.  
**Methods:** Analyses are ongoing of a large international palliative care patient cohort ( $n=1739$ ). Patients were followed for three months or until death. Medical data and patient reported outcomes were collected, including key cachexia parameters (weight loss, body mass index, anorexia, C-reactive protein levels and performance status). For each visit the patients were divided into groups adapted from the current cachexia classification, and a descriptive analysis was done. Survival analyses will be done on each group. Cox regression analyses will be used to explore factors associated with cachexia development.  
**Results:** 1058 patients (male 49%, median age 65, 37% Karnofsky score < 70) had complete data for the first month. 51% had no cachexia (NC) at baseline, 5% had PC, 32% had C and 11% had RC. After one month, 6% of patients with NC at baseline had developed C or RC, while 11% had died. 36% of patients with PC had developed C or RC, and 10% had died. The mortality was 19% and 51% for patients with C and RC, respectively.  
**Conclusion:** Patients with PC had higher risk of developing cachexia than patients with NC. The mortality was similar in both groups. The mortality was higher for patients with C and RC.  
**Funding:** Central Norway Regional Health Authority

**Abstract number:** FC17.5  
**Abstract type:** Oral

## Cancer Related Fatigue - Are we Offering Enough?

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**Background:** Cancer related fatigue (CRF) is a prevalent but under documented symptom. There is a misconception that little support can be offered. A fatigue interest group was established in a large cancer centre to raise awareness, (staff education and talking to patient support groups), to develop a fatigue pathway and improve patient experience.  
**Methods:** 2 surveys were conducted 1) 68 case notes were examined to determine the level of reporting of CRF and 2) 146 outpatients were given a questionnaire and the EORTC Fatigue measure (FA13) to determine the incidence, severity and impact of CRF and what interventions were routinely offered to cancer patients.  
**Results:** 29 (43%) of notes recorded patients experiencing CRF on at least one occasion but in only 2 cases was there evidence that patients had been given advice. From the 108 respondents in the prospective study 93 (86%) reported being advised to expect CRF during treatment, falling to 67% being asked again during treatment. 84 patients reported physical CRF, 55 emotional CRF and 43 cognitive CRF. 55% of patients experiencing CRF were offered advice. 52% were not offered a readily available booklet and of these 18 would have liked to see it. Despite the growing counter-intuitive evidence that exercise is a useful intervention there was no evidence to suggest its promotion. As a manifestation of their CRF, several patients expressed 'anger and frustration' saying they were confused or unable to think clearly. They also commented on the CRF's cyclical nature linked to treatment schedules.  
**Conclusions:** A gap remains in the support offered to patients. Lack of awareness of CRF from some clinical members of staff was found, including information and advice readily available at the cancer centre that can enable patients' to self manage their symptoms. Promoting awareness and education of CRF to patients, carers and health care professionals, could improve the overall patient experience of this distressing symptom.

**Abstract number:** FC17.6  
**Abstract type:** Oral

## Does Methylprednisolone 32 mg Affect Sleep Quality in Advanced Cancer Patients with Pain? A randomized, Controlled Trial

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**Background:** Corticosteroids (CS) are frequently used in palliative care. Patients using CS are at risk of side effects including poor sleep quality. The impact of CS on sleep has not been evaluated in palliative care patients. We conducted a double-blind randomised controlled trial evaluating the analgesic effect of corticosteroids in cancer patients. A secondary aim was to evaluate the effect of CS on sleep quality.  
**Methods:** Adult cancer patients with average pain intensity last 24 hours  $\geq 4$  (NRS 0–10) despite ongoing opioid treatment were recruited from five palliative centres in Norway. After randomisation, the patients received methylprednisolone 16 mg or placebo twice daily for seven days. Sleep quality was measured by Pittsburgh Sleep Quality Index (PSQI) (0–21) at baseline and at day 7. A PSQI global score of  $> 5$  is categorised as poor sleep quality.  
**Results:** A total of 592 patients were screened from April 2008 to January 2012. Fifty patients were included in the study. 49 patients could be evaluated for sleep quality at baseline and 46 at day 7. The mean age was 64 years and the mean Karnofsky index (0–100) was 66. 28 patients used sleep medication, 15 in the CS group and 13 in the placebo group. The mean baseline PSQI global score was 8.27 (7.13–9.40); 14 patients reported good, whereas 35 patients reported poor sleep quality. On day seven there was no difference between the groups in PSQI global score: CS group: 9.21 (7.14–11.28); placebo group 8.32 (6.62–10.01) ( $p=0.50$ ). Also the change from baseline was similar: CS group: 0.33 (–0.48–1.15), placebo group 0.45 (–0.41–1.32) ( $p=0.83$ ). Sleeplessness reported as a "yes" or "no" response was similar between the groups.  
**Conclusions:** In this cohort, 35 out of 49 cancer patients with advanced disease and pain reported poor sleep quality. Methylprednisolone 32 mg daily for 7 days did not affect the sleep quality as measured by PSQI.  
**Funding:** Telemark Hospital Trust

## FC18

## Palliative care for older people

Abstract number: FC18.1

Abstract type: Oral

**Symptom Burden in Elderly Patients Admitted to Hospice Care. A Cross Sectional Study***de Graaf E.<sup>1,2</sup>, Zweers D.<sup>1,3</sup>, de Graeff A.<sup>2,3</sup>, Daggelders G.<sup>2,4</sup>, Teunissen S.<sup>1,2</sup>*

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Elderly have less and later access to specialized palliative care services due to difficulties in palliative phase marking and identifying palliative care needs.

**Aim:** To investigate differences and similarities of symptom prevalence and intensity of hospice patients in four different age-groups ≤65, 66–75, 76–85 and >85, to ameliorate the quality of and access to hospice care for patients of all ages.

**Method:** A cross sectional study. Patients admitted from June 2007 to December 2014 to a high care hospice facility in the Netherlands, able and willing to self-assess symptom intensity within the first week after admission, enrolled in this study.

Prospectively collected data from the Utrecht Symptom Diary (USD), a Dutch adapted translation of the Edmonton Symptom Assessment System, were used, measuring symptom intensity of 12 symptoms and well-being on a 0–10 numerical scale.

**Outcomes:** Symptom prevalence (USD>0) and symptom intensity.

**Data analysis:** Descriptive statistics, Chi<sup>2</sup>, ANOVA and Kruskal Wallis. Significance: p<0.05.

**Results:** A total of 227/342 (66.4%) patients were included: 38% men, median age 74 (31–96; SD 12.782). Ineligible patients were more likely to be >85, life expectancy <7 days, ECOG performance status=4 or survival<2 weeks.

Patients suffered from 6.3 symptoms concurrently, 4.6 scored >3 on USD. Fatigue, dry mouth and anorexia were most prevalent and intense in all age-groups, except for <65 in which pain was more prevalent than anorexia. Patients <65 suffered from pain more often (p=0.01) and intense (p=0.05), and patients >85 suffered from anorexia more often (p=0.47).

**Conclusion:** Little differences between age-groups, underpin the need for individualised hospice care for all patients despite age. However, old and severely ill patients were less able to self-assess their symptoms, indicating a need for innovative strategies to assess symptoms and specific needs of elderly by collaboration with geriatric and primary care specialists.

Abstract number: FC18.2

Abstract type: Oral

**Factors Associated with End of Life Transition for Older Adults Living at Home: Analysis of Carers' Post-bereavement Survey***Evans C.J.<sup>1,2</sup>, Bone A.E.<sup>1</sup>, Yi D.<sup>1</sup>, Wei G.<sup>1</sup>, Gomes B.<sup>1</sup>, Maddocks M.<sup>1</sup>, Sleeman K.E.<sup>1</sup>, Wright J.<sup>3</sup>, Mc Crone P.<sup>4</sup>, Higginson I.J.<sup>1</sup>, on behalf of OPTCare Elderly*

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**Background:** Transfer to hospital in the last weeks of life is common for older adults in England. It is imperative to better understand individual and service factors associated with transition to enable older people to remain in their usual place of care.

**Aim:** To explore possible determinants of transition from home to institutional care setting in last weeks of life for people aged over 75 years.

**Methods:** Post-bereavement survey of carers to people aged over 75 who died in 2012 in the South of England (n=883). Subsample analysis of decedents whose usual place of care in last 3 months was 'own home'. Main outcome is death at home versus hospital/care home (hospice deaths excluded). Exploration of socio-demographic and illness factors (e.g. symptom burden) using multivariate modified Poisson regression.

**Results:** 235 decedents spent most of the last 3 months of life at home. The majority died from non-malignant conditions (71.9%) with mean age 86 years. 51.1% died at home and 48.9% transitioned in the last 3 months to a hospital (44.7%) or care home (4.3%). Death outside usual place of care was independently associated with increasing age (85–90 years [PR=3.4; 95% CI 1.9–6.1] and over 90 years [PR=8.4; 95% CI 3.8–18.3] versus 75–80 years), and symptom complexity with severity of breathlessness (PR=1.9; 95% CI 1.2–3.4) and difficulty communicating (PR=2.0; 95% CI 1.5–2.8).

**Conclusion:** Transition from own home to hospital at the end of life is common for older adults living at home (nearly 1 in 2 experienced this). Transition occurs most frequently for the oldest old and those with severe symptoms of breathlessness and difficulty communicating. This suggests inequalities in the provision of care and challenges of symptom control at home. To reduce reliance on hospital care at the end of life requires timely services responsive to increasing symptom distress and wider anticipation of end of life for adults of advanced age.

**Funder:** NIHR Research for Patient Benefit

Abstract number: FC18.3

Abstract type: Oral

**Patterns of Multidimensional Change towards the End of Life for Frail Older People***Lloyd A.<sup>1</sup>, Kendall M.<sup>1</sup>, Starr J.<sup>2</sup>, Murray S.<sup>1</sup>*

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**Background:** Patterns of physical decline have been proposed for those dying with cancer, organ failure and frailty. These have been expanded to include change across the other palliative care dimensions for those with cancer and organ disease but not for frailty. An understanding of changes across these dimensions would help to assess how a palliative approach could help frail older people.

**Aims:** To describe patterns of multidimensional change in the experience of frail older adults towards the end of life.

**Methods:** 76 in-depth qualitative interviews were carried out with 13 frail older participants and their key formal and informal carers repeatedly for 18 months. Participants were cognitively intact, community dwelling adults considered to be moderately or severely frail. The interviews were participant led, audio-recorded and fully transcribed. The 'voice centred relational' narrative method of analysis was used to compile case studies highlighting physical, social, psychological and existential change to suggest narrative trajectories.

**Results:** Three patterns of change emerged alongside a gradual physical deterioration:

1) The stable narrative represented a maintenance of psychological and existential well-being punctuated by brief dips that corresponded to physical changes or events. A gradual social decline mirrored physical deterioration.

2) The regressive narrative differed in showing a descent in psychological and existential well-being.

3) The tragic narrative showed a marked downturn in social, psychological and existential well-being just before death.

**Conclusion:** Patterns of multidimensional change for frail older people suggested by the narrative accounts differ from those described for deaths from organ failure or cancer. Understanding these patterns may highlight how to alleviate psychological, social and existential distress as frail older people reach the end of life in order to enable them to die before their stories become tragic. ESRC funding.

Abstract number: FC18.4

Abstract type: Oral

**End of Life Care for Frail Older Patients in Family Practice (ELFOP) – A Longitudinal Qualitative Study on Needs, Appropriateness and Utilization of Services***Klindtworth K.<sup>1</sup>, Müller-Mundt G.<sup>1</sup>, Geiger K.<sup>1</sup>, Bleidorn J.<sup>1</sup>, Pleschberger S.<sup>2</sup>, Schneider N.<sup>1</sup>*

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**Background:** Frail elderly people represent a major patient group in family practice. So far, little is known about the patients' needs and their possible changes over time with increasing frailty. The aim of this study was to prospectively explore the needs of frail elderly patients, their informal carers (ICs) and the perspectives of the involved general practitioners (GPs), focusing on the end of life. Funding: German Federal Ministry of Education and Research / 01GY1120.

**Methods:** The study uses a multiple-perspective, longitudinal qualitative design. Serial in-depth interviews with 31 elderly patients (72–95 years) with moderate to severe frailty, their ICs and GPs were conducted. Interviews took place every six months over a period of 18 months (max. 4 interviews per patient/IC/GP). Narrative and thematic analysis is conducted within and across cases.

**Results:** From the patients' perspective, frailty affects all aspects of life: the exhaustion of capabilities, increasing vulnerable health and symptom burden as well as social losses – interfering with patients' striving for sustaining their self, autonomy and participation. Over time, reliable in/formal support becomes increasingly important which means a substantial time effort for ICs and GPs. Thus, delivering care for frail elderly patients is demanding and complex due to multimorbidity, multi-medication and limited mobility. With increasing frailty, close cooperation among doctors and other professionals, such as nursing and medical assistants, is crucial to meet the complex patient needs.

**Conclusions:** Elderly patients with severe frailty need a comprehensive bio-psycho-social approach in health care. The results highlight the importance of generalist palliative care delivered by GPs. Focus groups and an expert workshop with health professionals and stakeholders will be finally held to develop strategies in order to sustain the provision of end of life care in family practice.

Abstract number: FC18.5

Abstract type: Oral

**Translating Knowledge into Practice: The Palliative Approach Toolkit***Parker D., Wilson J.*

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**Background:** Long term care facilities are able to provide end-of-life care for their residents. The Palliative Approach Toolkit is a knowledge translation product based on an evidence based model of palliative care and includes supporting educational products and implementation guidance.

**Aims:** The study reports on national after death audit data collected following one day workshops to instruct long term care staff on the implementation of the Palliative Approach Toolkit.

**Methods:** Pre-implementation after death audits for at least five residents per facility who died prior to the workshop date were provided. Post-implementation data is all resident deaths in each facility once the new model of care was introduced. After death audits provide information on place of death, transfers to hospital in the last week of life, documentation of end of life care wishes, use of a palliative care case conference and an end-of-life care pathway.

**Results:** Data for 468 pre implementation and 214 post implementation after death audits was analysed. There was no significant difference in place of death at the long term care

facility (86.5% vs 84.7%) or documentation of end of life wishes (71.4% vs 72.4%). While there was no difference in the number of transfers to hospital in the last week of life (18.9% vs 21.5%), residents did have shorter length of stays ( $\chi^2=10.79$ ,  $p<0.005$ ). There were significant differences in the number of residents who had a palliative care case conference (45.4% vs 59.7%,  $\chi^2=10.79$ ,  $p<0.001$ ) and commenced on an end-of-life care pathway ( $\chi^2=16.22$ ,  $p<0.001$ ) after the model of care was implemented.

**Conclusion:** The Palliative Approach Toolkit assists clinicians translate knowledge into practice and has reduced length of hospital stay in the last week of life and improved care planning through the use of case conferences and an end-of-life care pathway.

**Abstract number:** FC18.6  
**Abstract type:** Oral

## Older Adult Patients' Preferences for Accessing Specialist Palliative Care: Opportunities for Improvement

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**Background:** Older adult patients' access to specialist palliative care (SPC) services in acute settings is not ideal. Not all that require specialist input receive it. The extent to which patients' understanding of SPC, preference for SPC and associated behaviour results in access is unclear.

**Aim:** To explore how older patients' understanding of SPC, their preferences for SPC and their behaviour influences access to SPC services in acute hospitals in Ireland.

**Methods:** Principles of grounded theory analysis of interviews with patients over the age of 65 who had successfully accessed specialist palliative care in Ireland and that were sampled purposively as one component of an international study involving services in the UK, Ireland and the USA.

**Results:** Limited awareness of SPC and its role influenced, although did not determine, SPC access. However, awareness of SPC did influence whether patients could request SPC referral to their lead clinical team. Additional factors which influenced the access included: the patient's level of engagement with healthcare professionals (HCPs); previous experience with or accurate communication about SPC; staff prioritising relational aspects of providing care, which led to the identification of patient SPC need; and open communication about prognosis between health care professionals, patients and unpaid caregivers.

**Conclusion:** Improved understanding of the patients' perspective can help HCPs to tailor communication and information-sharing in a manner that addresses barriers to expressing needs and preferences. This can help HCPs identify palliative care needs and initiate access to services. Additionally, improved public awareness of palliative care services would help ensure that patients are sufficiently informed about the availability and suitability of such input.

**Funders:** Atlantic Philanthropies and Cicely Saunders International

**Abstract number:** FC19.1

**Abstract number:** FC19.2  
**Abstract type:** Oral

**The Carers' Alert Thermometer (CAT): An Instrument to Identify Family Carers' Needs Whilst Providing End of Life Care in the Home**

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**Background:** International policy promotes the choice of a home death for dying patients, placing substantial demands on family carers. Recognising the burden on carers, research has highlighted the need for effective support of family carers. To prevent crisis situations & avoid unnecessary hospital admissions, which are of global concern, it is necessary to identify carer needs and provide appropriate interventions to support them in their role. There are no evidence-based instruments used by non-specialist staff going into patients' homes to assess carers' needs whilst they provide end-of-life care.

**Aim:** To explore what professionals and carers of patients in their last year of life find burdensome & develop an alert system for use by non-specialist staff.

**Methods:** A mixed-method, multi-phased, consensus study sequentially utilising qualitative and quantitative data to develop and pilot the CAT involving 245 participants (117 carers & 128 professionals) across a range of health & social care settings in the North West of England (2011-2014).

**Results:** Participants identified a complex range of burdens across eight domains which fit within two overarching themes: the support needed by the carer to provide care and the support needed for the carer's own health and well-being. There was high agreement between carers and professionals on the priority burdens for detection by the CAT, which was supported in the pilot.

**Conclusions:** The varied and complex needs of carers are often unmet until a crisis is reached. The CAT is an evidence-based, short screening instrument of 10 questions with a traffic light system for risk of each alert and a visual thermometer to identify the extent of the carer's unmet needs. The guidance section can be tailored to local services and an action plan used to monitor interventions. Preliminary piloting of the CAT found it was valued, fit for purpose and could be administered by a range of staff. This paper will present the findings and ongoing implementation of the CAT.

**Abstract number:** FC19.3  
**Abstract type:** Oral

## Piloting a New Approach to Identifying, Assessing and Supporting Carers of People with Palliative Care Needs in Primary Care

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**Background:** UK general practices are incentivised to have a protocol for the identification of carers and a mechanism for referral for social services assessment. This is rarely done systematically and very few carers of patients with palliative care needs are identified. Thus they fail to receive support.

**Aim:** To model and pilot a systematic approach to identifying, assessing and supporting carers of people with palliative care needs in primary care.

**Methods:** The intervention was modelled on the MRC complex intervention framework which incorporates a preliminary theoretical phase. These findings are reported elsewhere. Four general practices which varied in size were recruited to pilot the intervention for 12 months. Each practice nominated a carer liaison to lead on carer identification and support.

**Results:** The practices varied in size from 5840 to 10832 patients. The carer liaisons were in clinical, administration and management roles. In total, 83 carers were identified across the 4 practices via registers; illness (13), palliative care (12), carer (11); advanced care plans (12) or opportunistically (28) at GP appointments or at home. Posters encouraging self-identification were displayed in waiting rooms and 7 carers self-identified. There were 55 female and 28 male carers. 33 cared for someone with dementia.

Overall, 81 carers received the intervention and 25 returned the Carer Support Needs Assessment Tool (CSNAT). On average, carers each identified 4/14 areas of need. 11 carers received a follow up call from the practice to discuss support. 12 carers were also referred for support.

**Conclusion:** Findings suggest that this new approach to identifying and supporting carers is deliverable in a primary care setting and works most effectively when embedded within the whole GP practice. A key challenge is the reluctance of carers to identify as such and to accept offers of support, although many felt better equipped to seek help in the future.

**Abstract number:** FC19.4  
**Abstract type:** Oral

## Short- and Long Term Effects of a Randomised Psycho-educational Intervention for Family Caregivers in Specialised Palliative Home Care

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**Background:** Family caregivers in palliative home care often face a heavy responsibility and

## FC19 Improving support for caregivers

**Abstract type:** Oral

## Shifts in Care Approaches and Attitudes at the End of Life of People with Intellectual Disabilities: From Activating Towards Caring and Letting Go

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**Background:** The focus in the care for people with intellectual disabilities (ID) is predominantly on self-reliance and participation. An increasing number of them will have life-limiting illnesses and will need palliative care, that requires another care approach.

**Aims:** The aim is to describe whether and how professionals and relatives change their care approach and attitudes when palliative care is needed.

**Methods:** Twelve cases of deceased people with ID were reconstructed from the perspective of a relative, doctor, nurse and/or social worker. Half of them died of cancer, while the others died from other chronic diseases or old age problems. The 45 interviews were transcribed verbatim and analysed inductively.

**Results:** Five major shifts in care approach were found:

- 1) Care staff and relatives had to let go of their usual care strategy and adapt to a focus on comforting care, taking over tasks and symptom relief;
- 2) The interweaving of emotional and professional involvement increasingly became a challenge for care staff;
- 3) There was heavy reliance on the joint interpretation of signals expressing distress and pain, as symptom relief became urgent and communication with the person with ID was often difficult;
- 4) The dependency of the person with ID became magnified in the perception of relatives, and medical decisions in particular led to relatives having an overwhelming feeling of responsibility;
- 5) The awareness grew that the person with ID actually had 'two families' who were letting go: relatives and the care staff.

**Conclusion:** Palliative care for people with ID involves curtailing expectations of participation and skill acquisition, and an increase in teamwork featuring intensified comforting care, symptom management and medical decision making. ID care services should invest particularly in the emotional support and expertise level of care staff, and in the collaboration between relatives and professionals.



a burden of caring for a person with incurable illness. Research has showed that there is a need for intervention studies to make family caregivers more prepared and competent for their situation.

**Aim:** To investigate the short- and long-term effects of a randomised psycho-educational intervention for family caregivers in specialised palliative home care.

**Methods:** A psycho-educational intervention with supportive and educative components was designed based on the theoretical framework of Andershed and Ternstedt. Family caregivers from 10 specialised palliative home care units were included. The intervention was delivered as a randomised control trial where family caregivers who agreed to take part in the study were randomised to an intervention group with three sessions or to a control group with standard support. Family caregivers were required to answer to questionnaires at baseline, upon completion and two months following the intervention. The questionnaires comprised instruments concerning family caregivers' feelings of preparedness, competence, reward, burden, health, anxiety and depression. A regression model based on robust variance estimates was conducted for all tested outcomes.

**Results:** 177 family caregivers completed all three measurements. Results showed that in the short-term follow-up, family caregivers in the intervention group had significantly better self-rated competence for caregiving and experience of health. In the long-term follow-up, the intervention group had significantly better self-rated preparedness for caregiving compared to the control group.

**Conclusion:** The results add to previous research that relatively short psycho-educational interventions could have important positive short- and long-term effects on family caregivers in palliative care.

**Funding:** This study was supported by the Erling-Persson family foundation

**Abstract number:** FC19.5

**Abstract type:** Oral

### Everyone his "Own Truth"; Comparison of Experiences Concerning the Last Days of Life in the Hospital

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**Background:** When patients die, relatives and health care professionals may appreciate the quality of the dying phase differently, but comparisons are rare.

**Aims:** Comparison of the experiences of bereaved relatives, physicians and nurses concerning the care in the last days of life.

**Methods:** A cross-sectional study (June 2009–July 2012), in a Dutch university hospital, among the relatives, physicians and nurses of patients dying in the hospital. Outcomes were the extent to which participants agree on patients' quality of life during the final 3 days of life (QOL3) and quality of dying (QOD) (both on a 0–10 scale), on awareness of impending death, and on end-of-life communication; and the relation between end-of-life communication and preparedness for life closure. Multilevel regression analyses, Cohen's Kappa, and Spearman's Rho were used for analyses.

**Results:** Data on all three perspectives were available for 200 patients (mean age of 69 years, 59% male and 54% dying from cancer). Concordance was in general poor. QOL3 scores from relatives (median (M) 3; Inter Quartile Range (IQR) 1–6) were lower than those from physicians and nurses (both M 5; IQR 3–6;  $p < 0.001$ ). Relatives' scores for QOD (M 7; IQR 5–8) were also lower than physicians' and nurses' scores (both M 7; IQR 6–8;  $p = 0.002$ ). 48% of relatives, 77% of physicians and 73% of nurses had been aware of the patient's impending death. Physicians more often reported to have informed patients and relatives of end-of-life issues than relatives indicated. When both physicians and relatives reported that physicians had discussed the patient's prognosis, relatives had more often been aware of impending death and present at patient's deathbed.

**Conclusion:** Relatives, physicians and nurses seem to have their 'own truth' about care for the dying. Professionals should put more emphasis on collaboration with relatives, on timely communication about impending death, and on verification of relative's understanding.

**Abstract number:** FC19.6

**Abstract type:** Oral

### Carers at Risk: Anxiety and Depression in Carers of Patients with Advanced COPD and the Relationship to the Caring Role

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**Background:** Chronic obstructive pulmonary disease (COPD) is a progressive condition which can lead to high carer burden. Anxiety and depression are higher in informal carers of patients with advanced COPD than in the general population. But we lack robust evidence of patient and carer factors that may be associated with poorer carer psychological health and how best carers can be supported.

**Aims:** To identify the rates and severity of anxiety and depression in informal carers of patients with advanced COPD and how they relate to key features of the caring role in order to identify and support at risk carers.

**Methods:** Mixed method interviews with a cohort of 115 informal carers of patients with advanced COPD recruited from a primary care population-base (East of England). Carer data includes duration and hours of caring, patient relationship, carer health, carer support from services, patient factors, Hospital Anxiety and Depression Scale (HADS: anxiety and depression), Preparedness for Caregiving Tool, and Carer Support Needs Assessment Tool. Quantitative data analysed with descriptive statistics. Purposively sampled qualitative data analysed using framework approach.

**Results:** HADS identified probable clinical anxiety in 27% of carers and probable clinical depression in 10%. The results of our ongoing analyses will report the relationship these higher than population norm rates with key variables in the caring role (such as hours and duration of caring, service support, patient factors, preparedness of carers to care, and carer support needs in advanced COPD) to enable identification of at risk carers.

**Conclusion:** This analysis will provide new evidence on the psychological health and

support needs of informal carers of patients with advanced COPD to enable identification of at risk carers and the development of services to enhance support for those providing informal care in advanced non-malignant disease.

**Funder:** NIHR and Marie Curie Cancer Care

**Abstract number:** FC20.1

## FC20

### Health services research and public health

**Abstract type:** Oral

### What Are the Patterns of Dying in Acute Stroke?

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**Background:** Implementation of stroke professionals' palliative care role outlined in the UK National Clinical Guidelines for stroke is challenged by uncertainty about prognosis. Creating knowledge about the typology of dying in acute stroke (defined as the first 28 days after stroke onset) may usefully complement models that predict mortality.

**Aims:** To identify the patterns of dying in acute stroke services, and explore patient and family carer experiences.

**Methods:** An observational study prospectively identified dying trajectories within acute stroke. Biographical, stroke and care episode data, including the type of dying trajectory for deceased patients, were collected from consecutive admissions. We classified death trajectories as sudden; rapid; episodic; slow decline; or other, particularised to an acute stroke context. Interviews were conducted with a sample of patients, family carers and bereaved relatives, exploring narratives of experience and initiation of end of life care. The study was conducted over a 6 month period in 4 UK acute stroke services.

**Results:** Of 686 admissions screened; 627 (91.4%) were eligible for inclusion. Six patients, nine family members and two bereaved family members took part in interviews. There were 91 deaths during the study period (14.5% of stroke patients) with dying trajectories classified for 72 deceased patients. Five (7.3%) were classed as sudden deaths; 64 (88.6%) as rapid; 2 (3.3%) as episodic and 1 (0.8%) as slow decline. Qualitative findings highlighted the significance that patients and families attach to clinical geography, including the type of care setting, in making sense of prognosis. A range of helpful messages from staff around planning for end of life care within a context of hope were reported.

**Conclusions:** The pattern of dying that acute stroke service staff encounter most is a rapid decline in a patient's condition, with a distinct terminal phase, although not set within a general context of deterioration.

**Abstract number:** FC20.2

**Abstract type:** Oral

### End-of-Life Hospitalisation for Patients Dying of Chronic Obstructive Pulmonary Disease, Heart Failure, and Cancer: A Nationwide Study

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**Background:** Most patients prefer to remain at home as much as possible at the end of life. Hence, hospitalisation in the last months of life may be seen as adverse events.

More knowledge is therefore needed on the characteristics and determinants of hospitalisations among terminally ill patients. The role of the underlying disease is of particular interest in this context as previous findings suggest that end-of-life care to non-cancer patients is suboptimal compared to patients with malignant diagnoses.

**Aims:** To compare use of hospital admissions within six months before death among patients who died of chronic obstructive pulmonary disease (COPD), heart failure, or cancer.

**Method:** We conducted a nationwide study based on linkage of national medical registries. We included all decedents in Denmark between 2005 and 2011 dying from COPD, heart failure, or cancer using the Danish Registry of Causes of Death. Data on all hospital admissions within six months before death were obtained from the Danish National Registry of Patients.

We computed the median number of days spent in hospital within the six months period. Finally, we compared the total length of hospitalisation adjusted for age and gender using linear regression.

**Results:** For deceased patients with COPD, heart failure, and cancer, the median number of days spent in hospital during the last six months before death was 14, 13 and 20 days, respectively. This corresponded to 7.2%, 7.8%, and 11.1% of the days within the last six months.

The adjusted relative length of stay was 0.59 (95% CI, 0.57; 0.62) for COPD patients, and 0.51 (95% CI, 0.48; 0.54) for patients with heart failure when compared with patients with cancer.

**Conclusion:** Patients with chronic obstructive pulmonary disease and heart failure spend less time at hospital at the end of life than cancer patients. More knowledge is warranted on differences in end of life care patterns among cancer and non-cancer patients.

**Funding:** Danish Heart Association.

Abstract number: FC20.3  
Abstract type: Oral

## How Do Healthcare Systems Evaluate their Advance Care Planning Initiatives? Results from a Systematic Review

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**Background:** Advance Care Planning (ACP) is a process of reflection and communication of a person's future healthcare preferences. ACP is being implemented across healthcare systems around the world. However, there is no consensus on what measures to use to assess the effectiveness, impact, and sustainability of ACP implementation.

**Aims:** To describe and synthesise the existing information on how health care systems have evaluated the implementation of conversation-based ACP programs/initiatives.

**Methods:** A systematic search of the peer-reviewed and grey literature (to March 2014) was conducted to identify articles describing the implementation and evaluation of a health system-level ACP initiative. Using the PICO model, 734 titles/abstracts from the peer-reviewed literature and 76 grey literature documents were screened, and 130 full text articles were assessed for eligibility.

**Results:** Forty articles met inclusion criteria for analysis. Most articles reported on single parts of a healthcare system only (e.g. most evaluations occurred in continuing care). The most common outcome measures pertained to document completion, followed by healthcare resource use and ACP service components. Patient-, family-, or healthcare provider-reported outcomes were less commonly measured.

**Conclusion:** Document completion is frequently used to evaluate ACP program implementation; capturing the *quality of care* appears to be more difficult, as is evaluation across complex, multi-sector healthcare systems. This systematic review provides health system administrators with a comprehensive summary of measures used to evaluate ACP, and may identify gaps in evaluation within their local context. In Alberta, these results are being used to inform a Delphi process to determine important indicators relevant to ACP uptake within the healthcare system, and further, to develop a dashboard for ongoing monitoring of ACP implementation and sustainability across the province.

Abstract number: FC20.4  
Abstract type: Oral

## Economic Evaluation of Palliative Care Consultation Teams for Patients Admitted to Hospital with Advanced Cancer

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**Background:** The average cost-saving effect of palliative care consultation teams (PCCTs) for hospital inpatients with serious illness is well known. This effect is not homogenous but varies according to a complex interaction of individual and service factors. Evidence on the relationship between patient-level determinants, PCCT process and cost will further inform organisation of hospital care to patients with serious illness.

**Aims:** To evaluate the impact of PCCTs on hospital cost, incorporating time-to-consult following admission and individual clinical factors.

**Methods:** Using a prospective, observational design, clinical and hospital cost data were collected for adult patients with an advanced cancer diagnosis admitted to five hospitals in the United States in a four-year period. The final sample was 969 patients; 256 saw a PCCT during their hospital admission, 713 received usual care only. Propensity score weights were calculated to balance treatment and comparison arms. Generalised linear models (GLMs) with a gamma distribution and a log link were applied to estimate association between treatment, patient covariates and cost.

**Results:** Earlier consultation is associated with a larger effect on hospital cost: an intervention within six days is estimated to reduce total costs by 13% (p=0.04) compared to no intervention and within two days by 23% (p<0.005) compared to no intervention. PCCT treatment effect also varies according to selected baseline covariates; effect on cost is larger for patients with a higher number of comorbidities.

**Conclusion:** PCCT treatment effect on costs is not homogenous. Our results complement a growing body of research on quality, survival and cost suggesting that early palliative care should be more widely implemented, particularly for patients with multi-morbidity. The potential for cost-saving through PCCTs is yet to be fully realised: only a quarter of patients in our study saw a PCCT promptly upon hospital admission.

Abstract number: FC20.5  
Abstract type: Oral

## Comparing the Ability of Australian General Practitioners to Predict Death of their Older Patients Using Intuition or a Predictive Tool: A Randomised Controlled Trial

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**Aims:** Effective end of life care requires timely identification, then appropriate planning. Screening of general practice (GP) patient lists may be feasible. Does a screening tool help this?

**Methods:** Randomised controlled trial of GPs using clinical acumen versus Supportive and Palliative Care Indicator Tool (SPICt) (modified to facilitate screening), to screen practice patients aged ≥70 years, plus those <70 known to life-limiting illness. Practice records were reviewed at 6 months to identify actual patient deaths. This was compared to data from the state based death registries. Telephone interviews with GPs explored the acceptability and feasibility of the intervention, and key stakeholder groups interviewed to discuss the role of GPs in end of life care.

**Results:** Forty GPs were randomised (19 intervention [I], 21 control [C]) Twenty-nine GPs, (I =12 and C=17) reviewed 1546 and 2873 patient records respectively. At 6 months, practice records showed I=44 (2.8%) and C=65 (2.3%) deaths (p=0.234). The proportion of patients identified at risk was higher in intervention (I=14.8%, C=5.5%; p<0.001), as was the proportion of deaths correctly identified (I=2.01%, C=0.94%, Pp=0.003). Positive predictive value, negative predictive value, sensitivity and specificity were 17%, 99%, 42% and 95% for the intervention group, and 13%, 99%, 70% and 87% for control. A significant number of deaths (50% in NSW) recorded in the deaths registry was not documented in practice records. Most GPs found the intervention tool useful, but time-intensive.

**Conclusion:** The use of the screening tool was more effective than intuition in identifying patients correctly. There was a high incidence of false positives in both groups, and the process was time intensive. Given that false positive responses require a clinical response from GPs, screening of GP records using either intuition or SPICt does not appear feasible. **Funding:** RACGP/ PC4 Research fund

Abstract number: FC20.6  
Abstract type: Oral

## Scaling-up Palliative Care for an Ageing Population: Proposals from the IMPACT Project

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**Aim:** To develop a model of service provision that will allow scaling-up of palliative care expertise to meet the needs of those dying from any clinical condition.

**Background:** Palliative care has developed around the needs of people with cancer, and those dying with other conditions have had less access to palliative care services. This is now changing, albeit slowly, but the inclusion of other conditions requires modification of palliative care services because of the scale of need, the challenging nature of these conditions, and the limited range of palliative care skills in community settings.

**Methods:** A mixed methods technology development approach used:

- 1) Critical synthesis of the research and policy literature
- 2) Interviews with national experts in policy, service organisation, service delivery, patient and carer interests, and research
- 3) Nominal groups of researchers tasked with synthesising data and modelling palliative care.

**Findings:** A generic model of palliative care with embedded quality indicators has been developed in the IMPACT project. The model includes features needed for the systematisation of palliative care for a broad range of life-limiting conditions:

- 1) The division of labour amongst practitioners of different disciplines
- 2) The structure and function of care planning
- 3) The management of risk and complexity using shared decision-making approaches
- 4) Boundaries between active treatment and palliative care and between palliative and end-of-life care
- 5) Support for patients, families and staff through the experiences of loss and bereavement.

**Conclusion:** Co-design of a generic model of palliative care places the person needing palliative care within a landscape of technical tasks, sources of expertise and support for emotional needs. The generic model will be described in this presentation, and proposals made for changes in health care policy, service organisation and delivery, and palliative care practice.



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# Poster Prize Abstracts

**Abstract number:** PA-1  
**Abstract type:** Poster Prize

## Analysis of Determinants of Impaired Role Functioning Across Prevalent Cancers

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**Background:** Cancers are associated with role functioning impairment, but its determinants are not well known.

**Aims:** To assess the determinants of role functioning in patients with prevalent cancers such as lung, breast and colo-rectal.

**Methods:** Observational study performed on subjects with one of the cancer types mentioned above and who agreed to participate. Role functioning was evaluated with the specific domain of the EORTC QLQ-30 along with other variables including age, gender, quality of life, presence of clinically significant fatigue. This latter was defined as having the score of at least 4 as assessed with the Edmonton Symptom Assessment System (ESAS).

**Results:** The sample included 79 (34 with lung cancer, 24 with breast cancer and 21 with colorectal cancer), with a mean age of 63.3, 37 females and a mean role functioning (RF) score of 54.4. RF was comparable in older versus younger patients, was more impaired in males versus females (39.6 versus 71.1,  $p < 0.001$ ) and in lung cancer subset versus breast or colo-rectal cancer (40.9 versus 50.4 versus 77,  $p < 0.001$  for first versus second or third). It was also significantly decreased in patients with clinically significant fatigue compared to those without (39.8 versus 78.3,  $p < 0.001$ ). Multiple regression analysis determined that clinically significant fatigue was the strongest predictor of impaired role functioning ( $r$  partial -0.48  $p < 0.001$ ) and that cancer type was also a significant predictor ( $r$  partial 0.32,  $p = 0.0043$ ).

**Discussion:** Previous analyses focused on psychological, and social variables and none took into account clinical factors.

**Conclusion:** Among determinants of role function fatigue and type of cancer were found to be strong predictors and this should be taken into consideration especially in a palliative care setting.

**Abstract number:** PA-2  
**Abstract type:** Poster Prize

## Survival Time after Diagnosis of Terminal Illness: A Nation-wide Danish Cohort Study

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**Introduction:** Life-threatening illness may be incurable in some patients. When the survival time for a patient with life-threatening disease is estimated as short, Danish patients may be granted drug reimbursement. The final stage of life is determined by a clinical assessment, and eligibility for drug reimbursement may be a key marker of this stage. To decide when a life-threatening illness has become terminal is an on-going challenge, which may vary according to diagnosis.

**Aim:** To describe the survival time, according to diagnosis, in patients for whom life-threatening illness has been assessed as terminal.

**Method:** The design was a historical cohort study of terminally ill patients >18 years of age, who had been granted drug reimbursement in 2012 (inclusion year). Patients were included from the date they were granted drug reimbursement. In total, 10,453 patients were followed until death or end of follow-up in June 2014. Survival curves were calculated using the Kaplan-Meier method. Patient survival time was then dichotomised, according to diagnosis, at a survival time cut point of 30 days, and data were analysed using a logistic regression model.

**Results:** Included patients had an overall median survival time of 56 days; the median survival time was 59 days for lung cancer, 81 days for prostate cancer, 75 days for breast cancer, 68 days for colorectal cancer, and 19 days for non-cancer disease. Compared to lung cancer, the crude odds of surviving longer than the first 30 days were 23% higher for prostate cancer, the same for breast and colorectal cancer, but 63% lower for non-cancer disease.

**Conclusion:** The vast majority of patients die during the first few months after receiving drug reimbursement, although the short-term survival differs according to diagnosis. Non-cancer patients are assessed to have terminal illness particularly shortly before their actual death. These findings underline the difficulties in predicting the survival time at the end of life.

**Abstract number:** PA-3  
**Abstract type:** Poster Prize

## Family Cohesion after Losing a Parent to Cancer as a Teenager and Long-term Health and Wellbeing

*Birgisdóttir D<sup>1</sup>, Fürst CJ<sup>1</sup>, Nyberg T<sup>2</sup>, Bylund Grenklo T<sup>2,3,4</sup>*

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**Background:** Among parentally bereaved children there is a vulnerable group of bereaved children that are at increased risk of negative consequences when compared to their normative peers. The most constant findings of mediating factors are related to the family function after the loss, including cohesion, warmth and connection between the surviving parent and bereaved children but the existing evidence is limited, especially when it comes to teenagers and youths' own perception on family cohesion and its long-term effects on health and wellbeing.

**Purpose:** To investigate self-perceived family cohesion the first year after a loss of a parent to cancer and its association to long-term health and wellbeing among youths that were bereaved six to nine years earlier, in teenage.

**Method and participants:** In this nationwide population-based retrospective study, 622 of 851 (73%) youths (aged 18-25) responded to a questionnaire six to nine years after losing a parent to cancer at the age of 13 to 16. Associations were assessed with univariable and multivariable logistic regression.

**Results:** Cancer-bereaved youths who perceived poor (no/little) family cohesion the first year after the loss, were likelier to have moderate to severe depression 6-9 years after losing a parent to cancer in comparison with those reporting good (moderate/good) family cohesion. They were also likelier to report low wellbeing, symptoms of anxiety, problematic sleeping, emotional numbness and dammed-up grief. This remained statistically significant after adjusting for a variety of possible confounding factors.

**Conclusion:** Perceived poor family cohesion the first year after losing a parent to cancer was strongly associated with long-term negative health-related outcomes among bereaved youth. To give attention to family cohesion and provide support, if needed, to strengthen family cohesion in bereaved-to-be families, might prevent long-term suffering in their teenage children.

# Poster Sessions

## (Poster Exhibition Set 1)

Pain  
Breathlessness  
Fatigue/weakness/cachexia  
Other symptoms  
Assessment and measurement tools  
Audit and quality improvement  
Basic and translational research  
Bereavement  
Communication  
Development and organisation of services  
Education  
Ethics  
Family and care givers  
International developments  
Medical sociology  
Health services research  
Policy  
Public health and epidemiology  
Spirituality  
Social care and social work  
Psychology and psychiatry  
Research methodology  
Volunteering  
Cancer  
Non-cancer  
Palliative care for older people  
Palliative care in children and adolescents

## Pain

**Abstract number:** P1-001

**Abstract type:** Poster

### Second Signatory for Controlled Medications: Can it Cause Hindrance to Good Breakthrough Pain Management?

*Abbas S.Q.*

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**Aims:** To establish that breakthrough analgesia is administered on an inpatient unit according to the guidance.

**Background:** EAPC guidelines suggest that in some cases the buccal or intranasal Fentanyl preparations are preferable to immediate-release oral opioids due to more rapid onset of action and shorter duration of effect. Fentanyl citrate sublingual Tablet (FST) is administered to control breakthrough pain (BTP) and a 'top-up' dose is administered in 15 minutes if the pain does not respond. However, the Nursing and Midwifery council (UK) recommends that for administration of controlled drugs (CD), a secondary signatory is required within secondary care. This data was collected to find out if second dose was administered in 15 minutes if needed.

**Methods:** Retrospective data was collected on patients at an adult palliative care unit, requiring second dose of FST. Information was collected from CD record books and patients' notes.

**Results and analysis:** Over a period of three months, 46 episodes of BTP requiring second dose of FST were recorded. A top-up dose was signed for at 15 minutes for only 13 (28.2%) episodes. A further 14 (30.4%) doses were signed for with five minutes delay (20 minutes in total from first dose). 19 (41.3%) doses were signed for after 20 minutes with a range of 25 – 50 minutes (10 – 35 minutes delay). Note that there will be a further delay in administering the dose.

**Conclusion:** The majority of patients have BTP for less than 45 minutes. After reporting, it takes time to get the medication to the patient. The second dose may be delayed further, causing pain prolongation. This delay is due to finding a second nurse to check medication. Possible solutions include:

- 1) Checking both doses out at same time and allow patients to self-administer after 15 minutes if necessary. Medication can be signed back in if not required.
- 2) Allowing a single nurse check for second dose.
- 3) Allowing patients with capacity to take control of their BTP analgesia whilst on an inpatient unit.

**Abstract number:** P1-002

**Abstract type:** Poster

### A Retrospective Audit to Assess Symptom Prevalence in Patients Who Receive Peripheral Blood Stem Cell Transplant

*Landa A.<sup>1</sup>, Chapman N.<sup>2</sup>, Daniel A.<sup>2</sup>, Haworth U.<sup>2</sup>, Ahmed A.<sup>2</sup>*

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**Background:** For many haematological cancers, Peripheral Blood stem cell transplant (PBSCT) therapy is used. This can be from the patient themselves or from a donor. PBSCT's can give debilitating and severe side effects such as mucositis, diarrhoea, nausea and vomiting; which can impact on the patient's recovery and wellbeing.

**Aims:** To establish the prevalence of symptoms in patients who receive PBSCT. To establish whether the Palliative care team is being involved for symptom management.

**Method:** Retrospective study looking at 32 adult patients (23 male, 9 female) who had received therapeutic PBSCT. Patient documentation and Oral Care Hygiene plans were used to assess the frequency and severity of the symptoms, up to 15 days post-transplant.

**Results:** Twenty five (78%) patients had some degree of mucositis post-transplant and only 7 (28%) of these had palliative care involvement. Eight (25%) patients had grade 3 or 4 mucositis (fluid only diet or unable to swallow due to pain) and 50% of these were referred to the palliative care team for symptom management. 35% of allogeneic PBSCT patients and 17% of autologous SCT patients had grade 3 or 4 mucositis. The mucositis severity was worst around day 12 post-transplant. Diarrhoea was a fairly common symptom with 13/32 (40%) patients having diarrhoea more than twice, 8/32 (25%) patients having diarrhoea more than 5 times and 5/32 (15%) patients having diarrhoea more than 10 times post-transplant. Vomiting was less common with 17/32 (53%) patients vomiting more than twice and 5/32 (15%) patients vomiting more than five times post-transplant.

**Conclusion and recommendations:** Symptom prevalence is high among patients who undergo PBSCT. However only a small proportion of these patients get referred to palliative care. Our recommendations include a specific guideline for management of PBSCT related symptoms and early referral to palliative care to reduce symptom burden and potential quicker recovery.

**Abstract number:** P1-003

**Abstract type:** Poster

### Management of Neuropathic Pain (NP) Using the Capsaicin 8% Patch in Patients at a Tertiary Cancer Hospital

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**Background:** Cancer patients experience NP due to the disease or its treatment and systemic treatments often offer partial analgesia and are limited with adverse effects. We

describe our experience using the capsaicin 8% patch to treat patients with cancer-associated NP over a period of four years.

**Methods:** All patients treated with the capsaicin 8% patch between June 2009 and January 2014 were included in the analysis. Pain levels were assessed using an 11 point scale as part of the PainDETECT questionnaire and the Clinical Global Impression of Change Scale.

**Results:** A total of 112 patients were treated with the Capsaicin 8% patch. Pain diagnoses included chemotherapy-induced peripheral neuropathies, post-surgical and post-radiotherapy pain, cancer pain with areas of focal NP, post-herpetic neuralgia and other neuropathic pains. Some patients had good results following a single application whilst most patients required multiple applications at three monthly intervals. Reductions in pain scores 4–8 weeks after treatment are given below (Table). The Capsaicin 8% patch was particularly effective in patients with chemotherapy-induced neuropathy (CIN). In most patients, analgesia was reported after 24–48 hours, was sustained and was associated with an increase in activities that were previously limited by pain. Significant reductions in the use of opioids and systemic NP medications were reported.

Type of pain	<50%	50-90%	>90%
Surgical (n=28)	6	14	8
CIN (n=46)	5	17	24
XRT (n=8)	1	2	5
PHN (n=16)	8	4	4
Others (n=14)	5	5	4
Total (n=112)	25	42	45

[Pain score reductions in patients with cancer treatment]

**Conclusions:** This is one of the largest case series of patients with cancer treated with the Capsaicin 8% patch, showing significant and sustained benefit across a variety of patients. The authors recommend the use of Capsaicin 8% patch for localised neuropathic pain for rapid relief of symptoms during oncology treatments. Further evaluation in this setting is warranted.

**Abstract number:** P1-004

**Abstract type:** Poster

### Where Should I Start? Reported Practices and Confidence of Medical and Non-medical Prescribers in Initiating Opioids for Pain in Palliative Care Patients

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**Background:** Pain is common in patients with advanced and progressive disease. Evidence suggests that pain remains under-treated. There is guidance on effective prescribing of opioids for pain in palliative care patients but what do prescribers really do and how confident are they in prescribing?

**Aims:** To assess medical/non-medical prescriber practices and confidence in prescribing opioids to palliative care patients in hospital and community settings.

**Methods:** All medical and non-medical prescribers (NMP), site-specific and community nurses at East Sussex Healthcare NHS Trust (joint hospital and community NHS Trust) are invited to complete an online survey (with reference to own prescribing, or advice given to prescribers). Survey questions derived from task group discussion are also adapted from a previous survey. Survey reminders were sent out at periodic intervals. Responses were collated and summary statistics reported.

**Results:** 115 responses were received from a wide variety of staff (includes 30% consultant; 37% junior doctor/ST-3; 17% NMP/specialist nurse; 16% other). More than half (53%) looked after palliative care patients on at least a weekly basis. 54% of respondents had initiated strong opioids in the last month. Nearly a quarter of all respondents were not confident in prescribing opioids. Only 20% provided patients with written information. More than 60% stated they would use standard release morphine initially. Over 60% co-prescribe regular laxatives, 70% prn antiemetics and 20% prn naloxone. Only 36% had received specific training in initiation of strong opioids for adult palliative care patients. 60% of all respondents would welcome future e-learning education and 52% lectures.

**Conclusions:** Opioids are commonly prescribed for pain in palliative patients but few prescribers reported receiving specific training and there was a lack of confidence in prescribing opioids for some. Resources and further education will be developed to improve confidence in prescribing and information given to patients.

**Abstract number:** P1-005  
**Abstract type:** Poster

## Use of Parenteral Sufentanil in a French Palliative Care Unit

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**Background:** According to the French Health Products Safety Agency, sufentanil (by parenteral infusion) is a suitable analgesic for substitution for parenteral morphine or oxycodone in case of intolerance or ineffectiveness. Nevertheless, there is little data on this subject.

The objective of this study is to describe the experience in the use of sufentanil in a hospital palliative care setting.

**Aims:** The aim is to assess reasons and conditions of sufentanil prescription in palliative care patients.

**Methods:** We conducted a retrospective study to identify every patient who received parenteral sufentanil during a 3-year period, between 2011 and 2014, in a palliative care unit of a French teaching hospital. Socio-demographic characteristics, main diagnosis, medications and hospital discharge were collected from their medical and electronic record.

**Results:** 656 patients were hospitalized over a 3-year period and 47 (7.16%) patients received parenteral sufentanil (intravenous or subcutaneous). Among patients receiving sufentanil, the mean age at admission was 68.01 year (sd ±15.39) and the main diagnosis was cancer for 38 patients (80.85%).

17 patients (36.17%) had not been receiving other parenteral opioids before.

Main reasons to prescribe sufentanil were: 'inadequate pain control' (85.11%), 'need of a short-acting opioid analgesic by subcutaneous perfusion' (29.78%), and both reasons for 7 patients (14.89%).

**Conclusion / Discussion:** In France, because of a limited number of parenteral opioid analgesics, palliative care clinicians tend to use sufentanil in patients with intractable pain. This study shows a larger use of sufentanil than the French recommendations. One of the main reasons is the easy use of sufentanil by subcutaneous perfusion.

**Abstract number:** P1-006  
**Abstract type:** Poster

## The Influence of Low Salivary Flow Rates on the Absorption of a Sublingual Fentanyl Citrate Formulation for BTcP

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**Background:** Salivary gland hypofunction may affect the absorption of drugs through the oral mucosa, which in turn may affect their clinical efficacy (eg, onset of action).

**Aim:** The aim of this study was to assess the pharmacokinetics of a sublingual fentanyl citrate formulation (Abstral®) in a group of cancer patients with salivary gland hypofunction.

**Methods:** Nine cancer patients with salivary gland hypofunction underwent a series of three pharmacokinetic studies with Abstral®: in the first phase the patients received no pre-treatment; in the second phase the patients were allowed to moisten the oral cavity before dosing; in the third phase the patients were given pilocarpine hydrochloride (saliva stimulant) before dosing. Fentanyl concentrations were measured using a method of high performance liquid chromatography with validated tandem mass spectrometric detection.

**Results:** The T<sub>max</sub> was longer, the C<sub>max</sub> was lower, the AUC<sub>0-30</sub> lower, and the AUC<sub>last</sub> lower in the phase involving no pre-treatment; the T<sub>max</sub> / C<sub>max</sub> / AUC<sub>0-30</sub> / AUC<sub>last</sub> were similar in the phase involving moistening of the oral cavity and the phase involving giving pilocarpine hydrochloride.

**Conclusions:** The pharmacokinetics of Abstral® appear to be negatively affected by the presence of salivary gland hypofunction, although the moistening of the oral cavity before dosing results in a pharmacokinetic profile similar to that seen with the giving of pilocarpine hydrochloride (saliva stimulant).

**Abstract number:** P1-007  
**Abstract type:** Poster

## Acupuncture for Pain Management

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**Background:** Patients with cancer seek complementary and alternative medicine, including acupuncture. We hypothesise that the meridian balance method (BM) electro-acupuncture (EA) alleviates pain, improves physical and emotional functioning in women with chronic pelvic pain (CPP). A review of the literature was undertaken to inform a clinical study.

**Methods and results:** Comprehensive literature searches on EA and pain yielded studies that demonstrated that endogenous opioid peptides in the central nervous system mediate its analgesic effect. Several large-scale studies and an individual patient meta-analysis on certain painful conditions have shown that verum acupuncture is only slightly more effective than sham acupuncture; both were more superior to standard care controls. Such studies and those before 2008 typically focused on the needling effects and ignored the context effects. It is now acknowledged that acupuncture is a complex intervention, which consists of a Traditional Chinese Medicine (TCM) Health Consultation plus acupuncture needling (acupuncture treatment). Clinical evidence supports the importance of context in health outcomes, for example, Kaptschuk demonstrated that a supportive patient-practitioner relationship provided symptom relief and enhanced quality of life in patients with irritable bowel syndrome. Taken together, these studies would suggest that the physiological effect of acupuncture needling and a supportive patient/healthcare provider relationship (the context effect) play a role in control of painful symptoms.

**Conclusions:** The above studies led to the reformulation of our hypothesis and study design: the meridian BMEA treatment alleviates pain, improves physical and emotional functioning, in women with CPP. A pilot study that is underway will examine the impact of TCM Health Consultation + BMEA, (context effect + electro-acupuncture needling) comparing it with TCM Health Consultation (context effect) and usual care only.

**Abstract number:** P1-008  
**Abstract type:** Poster

## The Effective Dose Ranges of Fentanyl Buccal Tablets Depending to the Buccal or Sublingual Route of Administration (RoA) and Reason of Sublingual RoA Choice - A Multicenter, Observational Study in Palliative Cancer Patients with Breakthrough Cancer Pain

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**Background:** Breakthrough cancer pain (BTcP) is a transient exacerbation of pain that occurs either spontaneously, or in relation to a specific predictable or unpredictable trigger, despite relatively stable and adequately controlled background pain. Fentanyl buccal tablet (FBT) is commonly used in buccal or sublingual (SL) regimen for BTcP treatment.

**Aim:** Primary objective: determine effective dose range of FBT according to the route of administration (RoA) due to the patient's state. Secondary objective: identifying the reason of sublingual (SL) RoA choice.

**Methods:** Multicenter, open-label, single arm, observational study performed in Q4 2013-Q1 2014 in 58 pain centers over 16 week (4 visits; V1-4) in Poland. 321 palliative cancer patients (aged 63,31y) were enrolled and 276 completed full observation. Frequency of BTcP (fBTcP), mean BTcP daily intensity (mBTcPi), effective FBT dose (eFBTd) and RoA (buccal or sublingual) were documented. The McNemar-Bowker and Wilcoxon paired tests were used.

**Results:** For the 82,6% of patients (n=251) the eFBTd was ≤200 µg at V2 and for 73,7% (n=196) at V4. There was no statistical difference in eFBTd depending on the RoA. The SL RoA was chosen in 11,8% patients (n=36) and only 0,99% (n=3) of them received FBT > 200 µg. At V2 the buccal RoA was used in 87,8% (n=267) and 18,7% of them received FBT > 200 µg. Patient's preference was the reason for choosing SL RoA in 91,9% (n=34). The mBTcPi decreased from 7,2 (V1) to 5,7 (V4) on a 1-10 visual analog scale (VAS). The fBTcP decreased significantly from V1 to V4 with 70,4% of patients reporting ≥3 episodes at V1 and only 42,5% at V4 (p< 0.001).

**Conclusion:** The eFBTd increased over time. There was no statistical difference in eFBTd between buccal and SL administration. fBTcP decreased (p< 0.001), mBTcPi was reduced by 21% on VAS 0-10 (p< 0.001) between V1-V4. SL RoA was mainly used due to patient's preference. Disclosure: It was the company sponsored study.

**Abstract number:** P1-009  
**Abstract type:** Poster

## Clinically Significant Drug-drug Interactions Involving Opioid Analgesics Used for Pain Treatment in Patients with Cancer: A Systematic Review

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**Background:** Opioids are the drugs most frequently used to treat pain in cancer patients, however, in some patients they can cause significant adverse effects and drug-drug interactions (DDIs). Still, no advice concerning the combination of opioids and other drugs are given in the current European guidelines.

**Aims:** To identify studies that report clinically significant DDIs involving opioids used for pain treatment in adult cancer patients.

**Methods:** Systematic searches were performed in Embase and MEDLINE through OvidSP, and in the Cochrane Central Register of Controlled Trials, from the start of the databases (Embase from 1980) through January 2014. Additionally, reference lists of the papers read in full text were hand-searched.

**Results:** Of 901 retrieved papers, 112 were considered potentially eligible, and finally 17 publications were included after full-text reading. In addition, 15 papers were identified from the reference lists. All of the 32 included publications were case reports or case series. On the base of their analysis, DDIs related to opioids were grouped into:

- 1/ sedation and respiratory depression (11 papers),
- 2/ other CNS symptoms (15 papers),
- 3/ impairment of pain control and/or opioid withdrawal (7 papers),
- 4/ other symptoms (3 papers).

Opioids most frequently reported to cause DDIs were morphine, fentanyl, and methadone. The most common mechanisms eliciting DDIs were alteration of opioid metabolism due to the effect on CYP3A4 activity, and pharmacodynamic DDIs due to the combined effect on opioid, dopamine, cholinergic, and serotonin activity in the CNS.

**Conclusions:** Evidence for DDIs associated with the use of opioids in the treatment of pain in cancer patients is very limited. Still, the cases identified in this systematic review give some important suggestions for clinical practice. Physicians prescribing opioids should recognise the risk for DDIs and if possible avoid polypharmacy.

The research received no financial support.



**Abstract number:** P1-010

**Abstract type:** Poster

## Spinal Analgesics to Intractable Cancer Pain: A Systematic Review

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**Aim:** This systematic review aimed to analyse the evidence to support the administration of analgesics given spinally to patients with intractable cancer pain, considering balance between analgesia and side effects.

**Methods:** Search strategy was based on words related to cancer, pain, spinal route, analgesic and side effects (Jan/Feb 2014). Databases: PubMed, Embase, and Cochrane. Inclusion criteria: randomised controlled trials,  $\geq 20$ , adults with cancer pain, failure with previous systemic opioid treatment, outcomes of long-term spinal analgesia and English language. Methods, results, quality of evidence, and strength of recommendation (Grade Working Group) were analysed.

**Results:** From 2142 abstracts, nine articles were analysed and divided in: 1) spinal combinations of opioid (morphine or sufentanil) and adjuvant analgesic (bupivacaine, clonidine, ketamine, neostigmine or midazolam) vs. spinal administration of opioid alone ( $n=4$ ), 2) single spinal drug (morphine or aqueous phenol) in bolus vs. continuous administration ( $n=2$ ), 3) single spinal drug (ziconotide) vs. spinal placebo ( $n=1$ ), and 4) spinal opioid (morphine or hydromorphone) combined with or without adjuvant analgesic (not specified) vs. other treatment than spinal therapy ( $n=2$ ). Intrathecal and epidural routes were described. All studies presented limitations, which affected studies' internal validity and grade of recommendation. However, they demonstrated better pain control during combination of opioid and clonidine or ketamine, analgesic continuous infusion, administration of ziconotide, and use of implantable intrathecal system. Side effects were described, but there were few significant differences.

**Conclusion:** There is a small number of studies and their outcomes provide low quality of evidence and, as a result, weak recommendation for using spinal analgesics in adult patients with cancer. Further investigation is necessary.

*Evidence-based Recommendations from EAPC. A project of the EAPC-RN.*

**Abstract number:** P1-011

**Abstract type:** Poster

## Is Radiotherapy Useful for Treating Pain in Mesothelioma? A Phase II Trial

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**Introduction:** Radiotherapy is often used to treat pain in malignant pleural mesothelioma (MPM), however there is limited evidence to support this. The aim of this trial was to assess the role of radiotherapy for the treatment of pain in MPM.

**Methods:** A multicentre, single arm phase II trial was conducted. Eligible patients fulfilled the following criteria: diagnosis of MPM; pain secondary to mesothelioma; radiotherapy indicated for pain control; over 18 years of age. Patients had assessments of pain and other symptoms at baseline, then received 20Gy in 5 fractions. Key follow up points were five and 12 weeks post treatment. The primary endpoint measure was assessment of pain at the site of radiotherapy. Secondary endpoints included effects on quality of life, breathlessness, fatigue, mood, toxicity and the radiological response.

**Results:** Forty patients were recruited from three UK oncology centres. In terms of the primary endpoint, 14 patients (35%) had an improvement in their pain five weeks post radiotherapy (ITT) however based on a complete case analysis, 47% (CI 28.3-65.7) of patients alive at week 5 responded to the radiotherapy. The improvement in pain was not associated with an increase in opioid dose ( $p = 0.328$ ). There was no improvement in other key symptoms or quality of life.

**Conclusions:** Radiotherapy for pain control in MPM is an effective treatment in a proportion of patients, however it has limited effect on other symptoms or on quality of life. Future studies examining differing radiotherapy regimens with a view to improving response rates are warranted.

**Abstract number:** P1-012

**Abstract type:** Poster

## Prevalence and Pharmacological Treatment of Neuropathic Pain in Cancer Patients Admitted to Specialized Palliative Care

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**Background:** Pain in patients with cancer is often related to a combination of nociceptive and neuropathic mechanisms. Studies show that compared with nociceptive pain, patients with neuropathic pain (NP) suffer higher pain intensity, experience worse quality of life and report greater impact on daily living even after controlling for pain intensity. However, so far NP has only been studied in less detail in patients with cancer. Our hypotheses are that cancer patients admitted to a Center of Palliative Care (CPC) are often suffering from clinically undiagnosed NP and are often receiving inadequate medication for this pain.

**Aims:** Aims of this study are to assess:

- 1) The prevalence of NP among cancer patients admitted to a CPC, and
- 2) The number of patients with NP who receive relevant treatment at the time of the first consultation in the CPC.

**Methods:** The study population is cancer patients with incurable metastatic or locally advanced disease admitted to CPC, 18 years old or above. Data are collected at the time of first consultation with CPC. Patients are categorised as having NP if they:

- 1) Score 'possible' or 'probable' that a neuropathic component is present according to EFNS

guidelines *and at the same time*

2) Score  $\geq 4$  or higher in the DN4 questionnaire. Patients with NP receiving tricyclic antidepressants or anticonvulsants are considered to receive relevant treatment.

**Results:** Three-hundred-and-three patients were admitted to CPC from June 2013 to October 2014. Fifty-two patients were excluded because they did not suffer any pain and 43 patients were excluded for other reasons. In total, 208 patients were enrolled in the study. According to the criteria, 72 patients (35%) were categorised as having neuropathic cancer pain. Out of those, 14 patients (19%) received relevant treatment for NP.

**Conclusion:** NP is highly prevalent and pharmacologically inadequately treated among incurable cancer patients admitted to a CPC.

**Abstract number:** P1-013

**Abstract type:** Poster

## The Effect of Lidocaine on the Abdominal Pain Caused by Peritoneal Dissemination

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**Background:** Abdominal pain due to peritoneal dissemination is often difficult to manage. We report eight cases where good analgesia was obtained with lidocaine.

**Aims:** To evaluate the effects of lidocaine on abdominal pain due to peritoneal dissemination.

**Methods:** Between February 2013 and August 2014, we investigated the dosage, efficacy, and side effects of lidocaine to treat abdominal pain associated with peritoneal dissemination. Lidocaine was administered to eight patients with gastric cancer (1), lung cancer (1), ovarian cancer (2), pancreatic cancer (1), malignant peripheral nerve sheath tumor (1), and adult T cell leukemia/lymphoma (1).

**Results:** All patients claimed moderate to severe abdominal pain (5/10-10/10) on a Numeric Rating Scale (NRS). Opioids had previously been administered to five of the eight patients. After confirming by challenge test (intravenous infusion of 1 mg/kg lidocaine) that lidocaine was effective in all patients, we started continuous intravenous infusion of 500 mg/day lidocaine. The five patients who had used opioids obtained good pain relief within one day (NRS : 0/10-1/10). Three patients who received lidocaine alone obtained partial pain relief (NRS : 2/10-4/10). However, when lidocaine was used in combination with opioids, their pain almost completely resolved. The median duration of treatment was 25.5 days (range 7-48). Typical side effects of lidocaine, such as neurological symptoms and bradycardia, were not observed in any of the patients.

**Discussion:** In Japan, the sensation of abdominal pain induced by peritoneal dissemination was found to be accompanied by changes in the expression of substance P and  $\mu$ -opioid receptors in the spinal cord of mice. In mice, the pain was not suppressed by morphine alone, but it was suppressed when morphine was used in combination with lidocaine. We suggest that clinically, lidocaine is very effective against abdominal pain due to peritoneal dissemination.

**Abstract number:** P1-014

**Abstract type:** Poster

## Management of Cancer Related Neuropathic Pain. Answers to the "Burning" Questions

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**Background:** Neuropathic pain is common amongst patients with cancer. Treatment is often challenging particularly due to the limited evidence specific to the management of cancer related neuropathic pain.

**Aims:**

- (1) To perform a systematic review to evaluate the current evidence base regarding the management of cancer related neuropathic pain.
- (2) To update the regional standards and guidelines for the management of cancer related neuropathic pain.
- (3) To audit current regional practice in relation to the management of cancer related neuropathic pain.

**Methods:** A systematic review of the literature was performed. MEDLINE was the database that was searched. The regional standards and guidelines for the management of neuropathic pain were then reviewed.

During February 2014 an audit via an online questionnaire was completed by healthcare practitioners in the region managing patients with cancer related neuropathic pain.

**Results:** Screening tools have not been validated for the diagnosis of cancer-related neuropathic pain. There is evidence to support the use of opioids either as monotherapy or in combination with adjuvant analgesics. There are no trials comparing the efficacy of different opioids.

Existing guidelines advise the use of anticonvulsants and antidepressants as adjuncts to opioid analgesia. There is Level 1 evidence for the use of Gabapentin, Pregabalin and Amitriptyline. Limited evidence for Clonazepam and Steroids. No evidence for Lidocaine, Capsaicin, Tapentadol and Paracetamol. There is no evidence for non-pharmacological interventions including the use of Hydrotherapy, TENS, Scrambler and Psychological interventions.

**Conclusion:** Cancer-related neuropathic pain is usually unresponsive or partially responsive to opioids. There is evidence for the use of adjuvant analgesics such as Amitriptyline, Gabapentin and Pregabalin. Evidence for the management of cancer related neuropathic pain is limited.

**Abstract number:** P1-015  
**Abstract type:** Poster

## Effects of Acetaminophen at Different High Doses (2.4 g-4.0 g/Day) on Cancer Pain and Hepatic Toxicity

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**Purpose:** The Japanese Society for Palliative Medicine has published a Clinical Practice Guideline entitled 'Clinical Guidelines for Cancer Pain Management'. In this Guideline, high-dose acetaminophen (2.4g - 4.0g/day) is recommended to treat pain from cancer. However, the effect of acetaminophen at different high doses on cancer pain as well as the potential hepatic toxicity has not been reported in Japan so far.

**Method:** This study was conducted to retrospectively investigate the effects of different high doses of acetaminophen on the patients with persistent cancer pain who were treated from April 2008 to September 2014, as well as on the activities of serum alanine aminotransferase (ALT) and serum aspartate aminotransferase (AST). Patients were divided into three groups who received acetaminophen at 2.4g/day (2.4g group, n=45), 3.2g/day (3.2g group, n=46), and 4.0g/day (4.0g group, n=20), respectively. Pain was scored with the numeric rating scale (NRS).

**Results:** No significant differences were observed between the 2.4g group, 3.2g group and 4.0g group regarding the incidence of Grade 3/4 hepatic toxicity (2.2% vs. 4.3% vs. 5.0%, respectively;  $p = 0.806$ ). Although two cases stopped taking acetaminophen due to the increases in AST/ALT activities (one in the 2.4g group and another in the 4.0g group), acetaminophen-induced liver failure and death did not occur in this study. In contrast, significant differences in the NRS score were observed before and after acetaminophen administration in the 3.2g group (n=18) and 4.0g group (n=9), but not in 2.4g group (n=16). The mean difference in the NRS score was 2.1 (95% CI, 1.4 to 2.9;  $p < 0.001$ ) in the 3.2g group, 1.6 (95% CI, 0.5 to 2.6;  $p = 0.019$ ) in the 4.0g group, and 0.4 (95% CI, -0.4 to 1.3  $p = 0.312$ ) in the 2.4g group, respectively.

**Conclusion:** Our findings indicate that acetaminophen administration at the dose of 3.2-4.0g a day may be safety and effective for the treatment of cancer pain.

**Abstract number:** P1-016  
**Abstract type:** Poster

## Oxycodone/ Naloxone Combination for the Management of Pain in Cancer Patients - Real-life Clinical Experience from Two Centres in UK and Malaysia

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**Background:** Opioid-induced constipation is a problem faced by cancer patients and combining Oxycodone with Naloxone (Targinact/ Targin) is a way of addressing this common side-effect. We describe our clinical experience and economic implications over the past 3 years using this drug. We are also reporting two cases of systemic side-effects of opioid-withdrawal when used in patients with liver metastasis, but with normal liver function.

**Methods:** We looked at the economic implications of switching over to combination drug including use of laxatives. A cross-section of the patients treated with the drug, who reported side-effects unrelated to the oxycodone, were also analysed for causality.

**Results:** Most patients had equianalgesic switch from Oxycodone or Morphine to the combination drug and did not experience any significant opioid-related side-effects. An average of 17 days elapsed before patients felt improvement in constipation and bowel movements. Patients using frequent rescue analgesia with oxycodone did not benefit much from the switch over compared to patients with stable analgesia. We observed much lower incidence of diarrhoea as compared to what was reported in clinical trials. Two patients had hospital admissions with symptoms and signs of opioid-withdrawal; liver metastasis was considered to cause porto-systemic communication resulting in naloxone getting into systemic circulation despite normal liver function.

**Conclusions:** Data from clinical practice from two centres showed that there is some cost benefit in switching to the combination drug especially at lower doses and in patients with stable analgesia. Drug is to be avoided or caution is to be exercised when using in the presence of liver metastasis due to systemic effects of opioid reversal by naloxone.

**Abstract number:** P1-017  
**Abstract type:** Poster

## Rapid Titration by Intravenous Administration of Oxycodone Injection in Cancer Patients with Severe Pain

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**Purpose:** Some cancer patients suddenly develop unbearable pain, and physicians must promptly cope with it. Rapid titration using morphine has been occasionally employed to control such severe pain. Oxycodone preparations have recently begun to be used instead of morphine as oral opioids for the management of cancer pain. The purpose of this study was to evaluate the effects of rapid titration using oxycodone injection in comparison with conventional titration using morphine injection.

**Methods:** The subjects were consecutive advanced cancer patients who consulted palliative care clinic or palliative care team due to severe pain (Numeric Rating Scale; NRS $\geq$ 8 and/or Support Team Assessment Scale; STAS=3-4) and were judged to require prompt pain relief. Rapid titration was performed with the method previously reported.

The evaluation items were; time needed until sufficient pain relief was obtained, pain relief success rate, and adverse effects. They were compared between the groups those treated with morphine injection (Morphine-group) and those treated with oxycodone injection (Oxycodone-group). 'Successful pain relief' was defined as alleviation of pain to NRS $\leq$ 3 and/or STAS=0-1.

**Results:** The opioid used for rapid titration was morphine injection in 28 cases (Morphine-group) and oxycodone injection in 15 cases (Oxycodone-group). The time needed until sufficient pain relief was obtained was 12 (4-28) minutes in Morphine-group and 10 (4-24)

minutes in Oxycodone-group. The pain relief success rate was 36 and 40% within 6 hours, 64 and 80% within 24 hours in Morphine-group and Oxycodone-group, respectively, showing no significant difference. As for adverse effects, nausea/vomiting, sleepiness, and respiratory suppression appeared in both groups, but they all occurred infrequently and were mild.

**Conclusion:** Prompt and safe pain relief could be achieved by rapid titration using oxycodone injection in advanced cancer patients and is considered to be one of the useful choices.

**Abstract number:** P1-018  
**Abstract type:** Poster

## Hypnosis Can Reduce Pain in Hospitalized Older Patients: A Randomized Controlled Study

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**Introduction and objective:** Chronic pain is a common and serious health problem in older patients. Treatment often includes non pharmacological approaches despite a relatively modest evidence base in this population. Hypnosis has been used in younger adults with positive results. The main objective of this study was to measure the feasibility and efficacy of hypnosis (including self hypnosis) in the management of chronic pain in older hospitalised patients.

**Methods:** A single center randomised controlled trial using a two arm parallel group design (hypnosis versus massage). Inclusion criteria were chronic pain for more than 3 months with impact on daily life activities, intensity of  $> 4$ ; adapted analgesic treatment; no cognitive impairment. Brief pain inventory was completed.

**Results:** 53 patients were included (mean age: 80.6 $\pm$ 8.2- 14 men; 26 hypnosis; 27 massage. Pain intensity decreased significantly in both groups after each session. Average pain measured by the brief pain index sustained a greater decrease in the hypnosis group compared to the massage group during the hospitalisation. This was confirmed by the measure of intensity of the pain before each session that decreased only in the hypnosis group over time ( $P=0.008$ ). Depression scores improved significantly over the time only in the hypnosis group ( $P=0.018$ ). There was no effect in either group 3 months post hospital discharge.

**Conclusion:** Hypnosis represents a safe and valuable tool in chronic pain management of hospitalised older patients. In hospital interventions did not provide long term post discharge relief.

**Abstract number:** P1-019  
**Abstract type:** Poster

## Vertical Limits: High Dose Opioid Treatment in Cancer Pain Management

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**Background:** Pain in cancer patients is one of the most frequent and distressing symptoms. Opioids play a major role for managing cancer pain. To avoid overdosing in a general population it is important to know limits of a reference range for typical opioid doses - characterising high dose opioid therapy beyond these limits.

**Aim:** Systematic review to define these limits based on the published literature.

**Methods:** We searched the literature and identified the dose ranges of different opioids. Only randomised controlled trials (RCTs) with variable opioid dosing for cancer pain management and numerical rating scales (NRS) for pain relief were included, when data on mean opioid doses (SD) were reported. Using the normal distribution theory according to Gau  , we calculated the 95% percentiles based on weighted mean and SD values. All mean and SD values were calculated after conversion to equipotent doses of oral morphine.

**Results:** Five studies matched our search criteria. We identified the following upper limits for a daily oral opioid dosage: morphine ~300 mg, hydromorphone ~40 mg, oxycodone ~150 mg.

**Discussion and conclusion:** We identified the upper limits of a reference range for a typical opioid pain therapy. Knowing these reference ranges may provide guidance for an adequate opioid regimen. Of course, opioids need to be titrated against pain focusing at side effects, and for selected patients high dose opioid treatment may be helpful and well tolerated. Methodological challenges included different conversion rates for the calculation of equipotent opioid doses.

# Poster Sessions (Poster Exhibition Set 1)

**Abstract number:** P1-020

**Abstract type:** Poster

## Efficacy and Safety of Tapentadol after Fast Titration in Patients with Multiple Myeloma and Bone Pain: Preliminary Results

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**Background:** Tapentadol (TP) is a new dual-action opioid. Although it has proven efficacy and safety in non-oncological chronic pain, evidence to support its use in cancer pain is scant and non-existent in multiple myeloma-related bone pain (MM-BP).

**Aim:** To assess the efficacy and safety of TP after fast titration in patients (Pts) with MM-BP.

**Method:** Pts on TP for ≤ 10 days with MM-BP and 'Average pain' > 4/10 (Verbal Rating Scale: 0-10) over the previous 72 h. were included in the study after signing the informed consent form. The strategy employed to achieve fast TP titration was to increase TP by 100 mg/p.o. every 3 days until reaching a maximum of 500 mg per day. 'Average' and 'Worst' pains and toxicity (CTCAE v.4.0) were assessed on days 0, +3, +6, +9, and +12 after inclusion. Primary efficacy outcome (%PID<sub>0-9+12</sub> ≥ 33%) was defined by a reduction ≥ 33% of the mean difference between 'Worst pain' score at day 0 and the mean score of days +9 and +12 (day 9-12).

**Results:** Eleven pts (8 females) were included and assessed. Median MM-BP duration was 12 months. Mean age was 69 yrs. Median glomerular filtration rate (GFR) was 63, with 5 (45%) pts below 60. Mean 'Worst pain' was as follows: on day 0, 8.3 (SD1.2) and on days 9-12, 4.9 (SD2.6). Mean 'Average pain' was as follows: on day 0, 5.6 (SD1.8) and days 9-12, 2.7 (SD1.7). The proportion of pts with %PID<sub>0-9+12</sub> ≥ 33% for 'Worst pain' was 54.5%, and for 'Average pain' = 72.7%. Mean number of daily episodes of breakthrough pain decreased from day 0 (2.9 episodes) to days 9-12 (0.4) (P=0.03). No differences in toxicity were found between days 0 and 9-12 (P=0.3). The mean doses of TP at day 0 and day 12 were, respectively, 127.3 mg (SD,75.4) and 213.6 mg (SD,145). The escalation index between day 0 and 12 was 44%. **Conclusions:** In a small sample of patients with MM-BP, a fast titration strategy of TP was both efficacious for pain control and safe, even with the presence of renal impairment frequently associated with MM.

**Abstract number:** P1-021

**Abstract type:** Poster

## The Prevalence of Oral Mucosal Disorders and Pain in 152 Patients with Advanced Cancer: A Prospective Randomized Study

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**Objectives:** The oral mucosal disorders, which xerostomia, mucositis and candidiasis, could represent disabling factors for cancer patients in advanced stages of disease. These disorders could be caused by drug therapies in particular anticancer ones. Also radiotherapy could cause mucositis and/or candidiasis. Pain is one of the most relevant symptom in cancer patients, and even though pain could be controlled for the whole day, it can present episodic exacerbation of pain. Oral mucosal disorders could cause absorption variability and consequently variability in efficacy of drugs administered by oral route also for pain. Our aim is to conduct an audit to assess the prevalence of oral mucosal disorders and pain in oncologic patients managed in Hospice (H) and palliative home care (CPD).

**Methods:** During a three months observation, all oncologic patients taken into care in H and CPD were asked a questionnaire.

**Results:** 152 patients have been considered for analysis (106 and 46 in home care and hospice respectively). The 51.3% were male, the mean age was 74.5 years (DS 12.1) and the performance status (as Karnofsky Index) was between 30-40% in both setting of observation. The 32.9% of patients had mucositis (from grade 1 to grade 4 of WHO grade); the major prevalence of the phenomenon was in patients in H (61%). The 46.1% of patients was affected of xerostomia (the 81% of this were in H). The 49% of the population had a background pain (50% in CPD and 43.5% in H), with an average of 2.1 points of NRS (DS 2.5). Breakthrough cancer Pain (BTCP) was registered in 21 patients in H (45.6%) and in 43 patients in CPD (40.5%); patients reported 3.42±3.66 BTCP episodes/day with a mean intensity of 6.1±1.84.

**Conclusion:** In palliative care is necessary to evaluate in clinical routine the presence of oral mucosal disorders, because of a best compliance of patients to treatments and to better dress the transmucosal therapy which could vary in absorption and consequently in efficacy.

**Abstract number:** P1-022

**Abstract type:** Poster

## Do Good Looking Doctors Provide Better Pain Therapy?

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**Background:** There is scarce evidence whether a doctors attractiveness impacts the efficacy of therapies.

**Aims:** Aim of this prospective matched cohort study was to test the hypothesis, that good looking doctors provide better pain therapy by means of significant pain reduction and enhancing quality of life. Secondary endpoints were reduction of anxiety, depression and change of overall wellbeing.

**Methods:** 200 physicians were selected by randomisation. Faces of the colleagues were digitally photographed in standardised manner. Each image was rated for attractiveness on a NRS-scale by 50 male and 50 female patients with advanced cancer. Physicians considered attractive > NRS 7 and physicians considered attractive < NRS 4 were matched with patients out of a standardised sample of cancer patients with bone pain greater NRS 7. Physicians faces were covered with facemasks while interacting to ensure a doubleblind setting. Pain treatment was performed within the framework of National Chinese Cancer Treatment Plan 8 treasures (NCCCTP-8). Pain intensity was measured by NRS, BPI, QOL was assessed with HRQOL and SF-36. Overall wellbeing was measured with ACSA, anxiety and depression

with HADS, Assessments were undertaken after periods of 1,7,14,21,60 and 120 days of treatment by blinded observers.

**Results:** Pain scores were significantly lower in the GLP-group beginning with day 7 of treatment (median 2,4 - SD ±0,76) compared to the BLP-group (median 5,77 ±2,2)(p<0.001). High significance in improvement of QOL was achieved by the GLD-group (p<0.0001). HADS changed significantly (p<0.01), ACSA remained in both groups at baseline.

**Conclusion:** Good looking doctors provided significantly better pain control than bad looking doctors. Depression and anxiety improved with treatment of an attractive physician. A limitation of the study was the fact that it was undertaken in a sole Asian country. Further research has to be undertaken to safeguard these data.

## Breathlessness

**Abstract number:** P1-023

**Abstract type:** Poster

## Effective Management of Breathlessness in Advanced Cancer Patient with a Program-based, Multi-disciplinary Approach: SOB Program in Hong Kong

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Breathlessness is common in advanced cancer patients. Because of its complex biopsychosocial etiology and manifestations, combination of both pharmacological interventions (PI) and non-pharmacological interventions (NPI) should be used. However, the intensive nature of NPI do limit the feasibility of implementation. To put theory into practice, the 'SOB Program' was started in our institution since April 2013.

**Objectives:**

1. Description of 'SOB Program'

The 'SOB Program' is designed for all advanced cancer patients (both in-patient and out-patient) with dyspnea, to improve their symptom and functional level. It involves palliative care doctors, nurses, occupational therapists (OT) and physiotherapists (PT). After treating the reversible causes, patients with Medical Research Council (MRC) Scale ≥2 are given suitable interventions. Besides medications, various NPI including breathing and relaxation training, positioning, use of fan, walking aids etc are offered. All out-patients would receive a 4-week follow-up phone call. Those needed home oxygen are referred to OT to learn proper use.

2. Outcome

From April 2013 to August 2014, 216 patients entered into the program (In-patient: 127 [58.80%], out-patient: 89 [41.20%]). 189 (87.50%) were offered PI and 193 (89.35%) were offered NPI. There was a significant increase in use of NPI (26.86% in Pre vs. 89.35% Post implement). The three most commonly used NPI were use of fan (97.92%), breathing and relaxation training (94.91%), and use of walking aids (60.10%). Specifically, we measured the subjective dyspnea relief in our out-patient group. 78 out of 82 patients (95%) who responded to phone follow-up had improvement (mean VAS percentage reduction: 31.66±10.93%, p<0.01; mean VAS absolute reduction: 1.91±0.7, p<0.01).

**Conclusion:** Breathlessness could be effectively managed by a program-based, multidisciplinary approach. The success of our 'SOB Program' is encouraging. Similar program can be considered in other palliative centres.

**Abstract number:** P1-024

**Abstract type:** Poster

## Continuous Intrathecal Morphine Infusion for Intractable Cancer Dyspnea

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**Aim of investigation:** We are using continuous intrathecal morphine infusion for pain management at our institution for patients with severe cancer pain. Among these patients, a few did not complain of dyspnea in spite of poor respiratory status, which is usually thought to cause severe dyspnea. On the basis of this experience, we speculated about the effect of continuous intrathecal morphine infusion on cancer dyspnea.

**Methods:** We performed continuous intrathecal morphine infusion for 11 patients with severe cancer dyspnea (mean age, 63.8 years). We evaluated the dyspnea by using the numerical rating score (NRS 0 to 10). All 11 patients experienced dyspnea with an NRS score ranging from 5 to 7 on lying down quietly. After lumbar subarachnoid puncture, we introduced an epidural catheter into the subarachnoid space, and started continuous morphine infusion. The daily morphine dose was calculated using one-hundredth of the calculated daily oral morphine equivalent dose used earlier.

**Results:** The final daily dose of morphine was 7 to 40 mg (mean dose 18.3mg). The duration of morphine infusion was 4 to 63 days (mean duration 16.6 days). In 8 of 11 patients, dyspnea improved to NRS 3 or less at rest without consciousness disturbance. This method was effective for the dyspnea due to hypoxia associated with lung metastasis or lymphangitis carcinomatosa of the lung. However, the palliation of dyspnea after movements such as walking was difficult.

**Discussion:** Intravenous morphine dose escalation for cancer dyspnea causes drowsiness. In this study, the consciousness levels of our patients were clear, thus, continuous intrathecal morphine infusion was found to be effective for patients with intractable cancer dyspnea. Pain management with intrathecal morphine infusion is particularly recommended in the case of patients who have intractable cancer pain and are likely to develop severe dyspnea.



Abstract number: P1-025  
Abstract type: Poster

### Assessing Referrals for 'Palliative' Oxygen Therapy

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**Background:** It is not unusual for breathless non-hypoxaemic palliative care patients to be prescribed oxygen despite a lack of evidence for this, other interventions being of proven benefit and the fact inappropriate oxygen therapy may be harmful.

#### Aims:

1. To assess the referral process for issuing domiciliary oxygen on discharge from hospital via a 'palliative' indication, comparing against local guidelines.

2. To examine what assessments and interventions are used for breathlessness in these patients.

**Methods:** A retrospective case note review of adults discharged from a teaching hospital with domiciliary 'palliative' oxygen over a 6 month period.

**Results:** 26 patients were included (age range 32-89 years). The majority (22/26) had a malignancy, the commonest being lung cancer (11/22). The remainder (4/26) had chronic obstructive pulmonary disease or heart failure. In the majority of cases the respiratory team (23/26) and palliative care team (23/26) were involved. Most patients (16/26) had a documented assessment of the severity of their breathlessness but in most cases (16/26) it wasn't documented whether oxygen improved this. The majority of patients were prescribed opioids (24/26) and benzodiazepines (22/26) on discharge. 8/26 patients were issued with domiciliary oxygen despite not meeting the criteria. Documented reasons for this included: poor prognosis, patient anxiety, patient request, symptom benefit, previous commitment from other health care professional.

**Conclusions:** Our findings suggest there are significant numbers of non-hypoxaemic palliative care patients being issued with 'palliative' domiciliary oxygen despite a lack of supporting evidence. We suggest education and support for patients and healthcare professionals regarding breathlessness management may be helpful, in addition to further research exploring views of healthcare professionals regarding oxygen therapy in non hypoxaemic patients and assessment of the clinical and economic implications.

Abstract number: P1-026  
Abstract type: Poster

### What is the Feasibility of Evaluating the Impact of a Breathlessness Service on Hypothalamic-pituitary-adrenal (HPA) Axis Function in Breathless Patients with Advanced Disease? A Mixed-methods Feasibility Randomised Controlled Trial (RCT)

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**Background:** Breathlessness is a common, distressing symptom. Services have been developed to reduce its impact through the delivery of combined therapies. The efficacy of such services is challenging to evaluate, suggesting a need for biomarker exploration. As breathlessness is often perceived as a stressor, we hypothesise that the stress system, as regulated by the hypothalamic-pituitary-adrenal (HPA) axis, becomes dysregulated in chronic breathlessness and is restored to normal following treatment. Measurement of the diurnal cortisol rhythm in saliva provides a window into this system.

**Aim:** To evaluate the feasibility of conducting an RCT investigating whether a breathlessness service improves HPA axis function in comparison with 'usual care' in breathless patients with advanced disease. Aspects of feasibility of interest include recruitment, compliance, attrition and acceptability.

**Methods:** A mixed-methods feasibility RCT is currently underway. Participants are randomised to either a breathlessness service or an 8-week waiting list control. Salivary diurnal cortisol profile measurements (10 samples over 2 days) are obtained at baseline and 8 weeks. Sampling compliance is assessed using sleep actigraphy. Acceptability is assessed through semi-structured interviews. Recruitment and attrition patterns and interview transcripts have undergone preliminary analysis. Compliance data and hypothesis-testing pilot data are pending.

**Results:** The trial opened in June 2013 and will close in Dec 2014. Of the 365 patients screened, 122 (33%) have been eligible and 28 (23% of eligible patients) have been enrolled. Ineligibility is most commonly due to oral steroid use (25%) or inpatient status (29%). Five patients (18%) have been withdrawn, most often due to commencement of oral steroids. Patients have found salivary sampling easy.

**Conclusion:** Recruitment has been slow and attrition high, but not prohibitively so. Overall, participants report a positive research experience.

## Fatigue/weakness/cachexia

Abstract number: P1-027  
Abstract type: Poster

### Association between Daily Physical Activity, Functional Capacity and Body Composition in Older Patients with Cancer Cachexia Syndrome

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**Introduction:** Aging is associated with increased incidence of cancer and one of the most ominous aspects of this disease is the cancer cachexia syndrome. The influence of body composition and measures of muscle quality on spontaneous daily activity is not well understood in this syndrome.

**Objectives:** To assess the spontaneous daily physical activity of non-cachectic and cachectic older people and to verify its association with body composition, muscle strength and functional capacity.

**Methods:** Exploratory cross-sectional study with 45 participants (24 non-cachectic, being 12 women and 21 cachectic, being 11 women) aged 65 years or over. Body weight, height, composition (DXA), handgrip strength, lower limb strength and functional capacity (Short Physical Performance Battery, 6-minute walking test (6MWT) and Instrumental Activities of Daily Living) were assessed. Spontaneous physical activity was monitored for 7 days by a device (ActivPAL, PAL Technologies, UK) that records time sitting/lying, time standing, time walking and number of steps taken.

**Results:** In non-cachectic men, there was a negative association between time walking with handgrip strength, lower limb strength and 6MWT; number of steps was also negatively associated with 6MWT and time sitting/lying positively associated with lean mass and 6MWT. In the cachectic group there was a negative association between fat mass and time standing and walking. In non-cachectic women, the time sitting/lying was positively associated with lean mass and time walking and number of steps with fat mass. In the cachectic group there was a positive association of number of steps and handgrip strength.

**Conclusion:** Cancer-cachexia was associated with a worse performance in parameters of spontaneous physical activity, which were associated with different measures of muscle quality. The non-cachectic group had a paradoxical positive correlation between lean mass and sedentary time, which has been described in other studies.

Abstract number: P1-028  
Abstract type: Poster

### The Three Ps - Occupational Therapy Approaches to Fatigue Management in Cancer and Palliative Care

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**Background:** Fatigue has been identified as one of the most common, and limiting symptoms for cancer/palliative care patients (Stone and Minton, 2008). The type and level of occupational therapy intervention for fatigue management varies between healthcare settings, and there is not a widespread understanding of this area of practice (Purcell et al, 2010).

**Aim:** To identify the evidence for fatigue management with this patient group in order to implement evidence based OT fatigue management interventions within a hospice out-patient and in-patient setting.

**Methods:** A literature search using a range of databases was carried out with the assistance of the hospice library services, using a combination of search terms including 'fatigue', 'cancer', 'oncology', 'palliative care', 'energy conservation' and 'occupational therapy'. The author and another occupational therapist reviewed the article abstracts and the full text versions of the most relevant articles.

**Results:** There was no consensus within the literature on the optimum method for delivering fatigue management. There was a mixture of individual face to face and telephone interventions, and group education programmes, with some promising evidence for an improvement in fatigue levels (Saarik and Hartley, 2010). Typically patients participated in 3 or 4 sessions (Barsevick et al, 2004).

**Conclusion:** Occupational therapists have a key role to play in assessing and managing fatigue. Intervention typically includes 3 or 4 sessions including education on energy conservation strategies such as prioritising, planning and positioning, with a focus on maximising engagement in meaningful activity. Individual and group approaches are both commonly used. Studies within this area are small and often not well described, therefore more research is needed. The author is implementing a review of the fatigue service provided within the hospice as a result of the evidence.

**Abstract number:** P1-029

**Abstract type:** Poster

## Cancer Cachexia, Body Image and Self-esteem

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**Background:** Distortions of body image that the individual designs for themselves are troubling and may reflect dissatisfaction with himself, changing their self-esteem.

**Aim:** To compare body image and self-esteem in patients with and without cachexia.

**Methods:** Cross-sectional study conducted between 2013-2014 with 378 adult patients with cancer of the digestive system and KPS $\geq$ 60%. Patients were classified into pre cachexia (pre-CACS, n = 53), cachexia (CACS, n = 122) and no CACS (n = 203) groups, as proposed by Fearon (2011). The body image was assessed by the Stunkard's Silhouettes Scale (domains distortion and satisfaction with body size) and self-esteem by the Rosenberg's Self-Esteem Scale (low, moderate and high).

**Results:** The patients were men (55.3%), aged 52y (SD = 10), most had not metastasised and was not in anticancer treatment. Tumors of the colon and rectum were prevalent in pre-CACS and no CACS groups; tumors of the stomach and esophagus prevailed in CACS group. Between 20% to 30% of patients in the 3 groups, the body image self assessment corresponded to BMI. In pre CACS and CACS groups, 45.3% and 64.8%, respectively, underestimated their body size. In the group no CACS, 38.4% overestimated. The desire to increase body size occurred in 80.9% in CACS group and in 50.9% of pre CACS group. Desire to decrease body size occurred in 44.3% of the group no CACS. In the three groups, the majority of patients (88.7%, 82.0% and 78.8%) indicated high self-esteem.

**Conclusion:** A significant number of patients showed body image distorted and the reasons and the impact of this distortion will be investigated. The high self-esteem observed in the 3 groups suggests little relationship between body image and self-esteem.

**Abstract number:** P1-030

**Abstract type:** Poster

## Multidisciplinary Programme for Intervention of Fatigue in Palliative Care Patients Using Biopsychospiritual Approach

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**Background:** Fatigue is a prevalent symptom in cancer palliative care, yet responds suboptimally to treatment. Physical fatigue is well recognised but difficult to ameliorate. The non-physical causative factors are neglected and need intensive palliative care approach.

**Aims:** To screen and identify all the underlying causes and evaluate the results of a multidisciplinary specialist-led programme in treating fatigue in palliative cancer patients. The programme utilises a structured biopsychospiritual approach, addressing the physical, psychological, social and spiritual needs.

**Methods:** A 'fatigue' team is dedicated to review and manage patients' fatigue. All cancer patients consecutively admitted with fatigue numerical rating scale of  $\geq 2$  were recruited. Each case is reviewed in depth. A checklist and care plan were incorporated to elucidate the causes. An individualised treatment support plan was initiated. Outcome measures include Brief Fatigue Inventory, Fatigue NRS, Modified Functional Assessment Capacity, PPS, Hospital Anxiety and Depression Scale, and McGill Quality of Life Score. A pilot programme was commenced, and the baseline and 2 week results were compared.

**Results:** 31 consecutive cancer patients were recruited. 14 could not complete 2 week programme due to early discharge or death. 17 patients completed two week programme. Mean age was 63. Commonest cancers were lung, breast and cervix. Commonest causes of fatigue were deconditioning, insomnia, pain, mood, chemo/RT side effects and sedatives. After 2 weeks intervention programme, the mean worst level of fatigue was successfully improved from 7.4 to 6.3 (p=0.018). As for impact of fatigue, improvement was seen in walking ability from 7.1 to 5.9 (p=0.005), and enjoyment of life from 7.5 to 6.1 (p=0.005).

**Conclusions:** A multidisciplinary structured palliative programme can reduce fatigue and impact of fatigue in palliative cancer patients within 2 weeks. Fatigue benefits from regular screening and intensive team support.

## Other symptoms

**Abstract number:** P1-031

**Abstract type:** Poster

## Acotiamide Hydrochloride Hydrate Suppresses Anorexia Induced by Cancer Cachexia in Humans

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**Background:** Acotiamide (nonproprietary name: acotiamide hydrochloride hydrate) is a new chemical entity, which inhibits peripheral acetylcholinesterase activities. Acetylcholine is an important neurotransmitter to regulate gastrointestinal motility, and through the inhibition of degradation of acetylcholine, Acotiamide improves the impaired gastric motility and delayed gastric emptying, and consequently the subjective symptoms of functional dyspepsia such as postprandial fullness, upper abdominal bloating, and early satiation. Anorexia is one of the most common symptoms of patients with advanced cancer and it presents as loss of appetite due to satiety. Acotiamide might improve cancer cachexia induced anorexia due to the same mechanism.

**Aims:** The aim of this study was to investigate the effects of Acotiamide on anorexia induced by cancer cachexia in humans.

**Methods:** The study was performed as a crossover design, ten cachectic patients with anorexia were randomly divided into two groups. Group A (n=5) received Acotiamide (100mg three times daily, orally) for two weeks followed by the control period without Acotiamide. Treatment with reversed order was performed for Group B (n=5). The amount of oral intake of each meal was observed and scored by 11 stages from 0 to 10 by nurses, and average oral intake during 14 days with or without Acotiamide was calculated and analysed. The results were expressed as the mean  $\pm$  the standard error of the mean. The Student's t-test was used to test for the significance of differences between groups. A P value < 0.05 was considered statistically significant.

**Results:** The average oral intake in the Acotiamide-on period was significantly larger than that in the Acotiamide-off period. This tendency was similarly seen in group A and group B, and neither an order effect nor a carry-over effect was seen.

**Conclusion:** Acotiamide appeared to prevent anorexia induced by cachexia, and have an effect on quality of life improvement and comfort in patients with advanced cancer.

**Abstract number:** P1-032

**Abstract type:** Poster

## Can Hospice Management of Ascites Alter the Patient Journey?

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**Background:** Ascites is a common problem for cancer patients often requiring paracentesis (P). Specialist palliative care units (SPCUs) offer an alternative to hospitals for this procedure.

**Aims:** To assess the performance of day case P at an SPCU and compare these patients with a national cohort with regard to prognosis and place of death.

**Methods:** In our SPCU we ultrasound patients, perform P and discharge them the same day. For 2 years from November 2010 we collected data about P.

A comparable national cohort was studied by using data from the joint Office of National Statistics-Hospital Episode Statistics database. All people dying of cancer for the same 2 years were selected who had a treatment code for P within a year of death. Kaplan-Meier survival analyses were performed to calculate median life expectancies.

**Results:** SPCU-28 had a P and 27 died during follow up-14/27 (52%) at home  
Median survival 42 days post-P

National-12,452 had a P within a year of death-27% died at home (p=0.004)  
Median survival 39 days.

Median survival (days): ovarian 93, breast 32, lung 30, colorectal 38

**Conclusion/discussion:** P can be managed successfully in an SPCU as an outpatient. Those managed in an SPCU were more likely to die at home and less likely to die in hospital when compared with those who had P in hospital during the last year of life. Perhaps those willing to come to an SPCU would want to engage with palliative care and would be more likely to die at home. It might be that engagement with our service changes the disease journey for patients. The only way to answer the question about the better location for ascites management for patients with palliative care needs is a trial where patients are randomised to hospital or SPCU. Any trial should assess health resource utilisation in addition to quality of life.

The longer survival of ovarian cancer patients is of note. These patients may have more to gain from earlier consideration of semi-permanent drain placement.



**Abstract number:** P1-033  
**Abstract type:** Poster

## Death Rattle

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**Introduction:** Death rattle is a term used to describe the noise produced in dying patients by the oscillatory movement of secretions in the upper airways. It is generally seen only in terminal patients with decreased consciousness. It is a frequent clinical sign occurring in 25-92 % of dying patients. Evidence shows that antimuscarine drugs can decrease the death rattle but there is no evidence whether aspiration of the secretions in hypo pharynx can decrease it. There is a reluctance to aspirate because it is thought to increase the secretions. For some relatives death rattle is hard to witness.

**Aim:** We aimed to assess the effectiveness of aspiration of hypo pharynx to reduce the sound of death rattle in the dying patient.

**Patients and methods:** Over one year terminal ill patients submitted to Hospice were included, when death rattle of intensity score 1 or more developed within the last 48 hours of life using the Victoria Respiratory Congestion Scale. All patients were clinically scored by the VRCS before aspiration and after aspiration. The patients and the relatives reaction to the aspiration was noted. Due to ethical considerations repositioning and antimuscarine (glycopyrronium) were used as well if it was considered to reduce suffering. We were aware that this might be bias and if using these other treatments, it was noted.

**Results:** From the data on the 18 patients, it seems that aspiration reduces death rattle when used alone and when combined with repositioning and glycopyrronium before aspiration. Death rattle decreased in 72% of the patients.

Five of the 18 patients responded to the aspiration and some of these patients can have been bothered by being aspirated.

All the relatives responded positively to the aspiration.

**Conclusion:** Aspiration can help to minimize death rattle in dying patients in the last 48 hours of life and it helps the familie to be with the patient. Further research on the influence of repositioning is needed.

**Abstract number:** P1-034  
**Abstract type:** Poster

## Constipation in Specialised Palliative Care: Prevalence, Definition and Patient Perceived Symptom-distress

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**Context:** The prevalence of constipation in palliative care has varied in prior research, from 18-90%, measured with both a frequency- based and a patients- perceived definition.

**Objectives:** The aim of this study was to describe and explore the prevalence and symptom-distress of constipation, using different definitions of constipation, in patients admitted to specialised palliative care settings.

**Methods:** Data was collected in a cross- sectional survey from 485 patients in 38 palliative care units in Sweden. Variables associated with distress and definition were analysed using logistic regression and summarised as odds ratio (OR).

**Result:** The prevalence of constipation varied between 7-43%, depending on the definition used. Two constipation- groups were found:

- (i) Medical constipation- group (MCG;  $\leq 3$  defecations/week,  $n = 114$ ; 23%);
- (ii) Perceived constipation- group (PCG; Patients with a perception of being constipated the last two weeks;  $n = 171$ ; 35%).

Three sub- groups emerged: patients with

- (a) only Medical constipation (7%),
- (b) only Perceived constipation (19%) and
- (c) with both Medical and Perceived constipation (16%).

There were no differences in symptom severity between groups; 71 % of all constipated patients had severe constipation.

**Conclusion:** The prevalence of constipation may differ, depending on the definition used and how constipation is assessed. In this study we found two main groups and Three sub-Groups, analysed from different definitions of frequency of bowel movements and experience of being constipated. To be able to identify constipation, the patients definition has to be further explored and assessed.

**Keywords:** Palliative care, constipation, prevalence, definition, symptom- distress

**Abstract number:** P1-035  
**Abstract type:** Poster

## Is Gabapentin Effective for Uraemic Pruritus? A Systematic Review

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**Background:** Uraemic pruritus is highly prevalent and is a particularly challenging symptom in patients with Chronic Kidney Disease (CKD). The neuropathic hypothesis of uraemic itch suggests that neuropathic agents may be effective in treating this symptom. Gabapentin is a drug that is used widely in palliative care for neuropathic pain and has been suggested as a treatment for uraemic pruritus.

**Aim:** To identify, review and assess the effectiveness of Gabapentin for reducing pruritus or itch in patients with CKD.

**Method:** A limited systematic literature review of randomised and controlled clinical trials published in English was undertaken. Medline, Embase and the Cochrane library were searched from inception to March 2014, in addition to hand searching. Studies were included that used Gabapentin as the intervention and reduction in pruritus score as the outcome measure. The population was patients with CKD (all stages). The Studies were then reviewed using the Effective Public Health Practice Project (EPHPP) Quality assessment tool for quantitative studies.

**Results:** Of 46 screened references, 3 studies (2 RCT and 1 CCT) were analysed. The total number of participants was 93, all with stage 5 CKD, on haemodialysis. All studies compared Gabapentin with placebo, in varying dosing schedules. All studies showed statistically

significant (p values set at  $< 0.05$ ) improvement over 4 weeks in mean pruritus scores on the visual analogue scale compared with placebo. There was methodological failing in one RCT, which importantly failed to describe how many patients received the intervention. Side effects were generally short lived but included somnolence, dizziness and fatigue and in one study caused two patients to drop out.

**Conclusion:** There is limited evidence of moderate quality for the effectiveness of gabapentin in reducing pruritus in patients with CKD. A larger RCT using gabapentin as the intervention for pruritus in this disease group is warranted.

**Abstract number:** P1-036  
**Abstract type:** Poster

## Attitudes and Beliefs of Palliative Care Physicians in the UK and Ireland towards Artificial Hydration at the End of Life

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**Background:** Artificial hydration at the end of life (AHEoL) is controversial due to a lack of robust scientific evidence and complex ethical considerations. This has been further highlighted by recent media attention.

**Aim:** To assess the current attitudes and beliefs of Palliative Care physicians in the UK and Ireland towards AHEoL.

**Methods:** A questionnaire survey of members of the Association for Palliative Medicine of Great Britain and Ireland was conducted from April to June 2014.

**Results:** A total of 294 questionnaire responses were received (36% response rate). The majority of respondents were consultants practicing across hospital and/or hospice sites. 92% of respondents had prescribed AHEoL in the past 12 months. 56% reported that patients were routinely assessed for AHEoL. 73% had experience of being approached directly by patients and all had at some point been approached by family members or caregivers about the use of AHEoL. 89% agreed that decisions around AHEoL must be discussed with the patient if possible and 90% agreed that decisions must be discussed with family members. However only 56% reported regularly discussing AHEoL with patients and/or their families. When asked about whether AHEoL worsened symptoms at end of life, 78% responded 'maybe' rather than 'yes' or 'no', while 71% responded 'maybe' when asked if AHEoL improved symptoms. 46% felt that the religious or cultural beliefs of the patient/family had influenced their prescription of AHEoL. 14% reported that their own religious or cultural beliefs may influence their attitudes towards AHEoL. 21% felt recent media response to end of life care had influenced decision making around AHEoL. 61% agreed that a guideline for AHEoL could be a useful tool for end of life care planning. **Conclusions:** This survey highlights the importance of an individualised plan of care supported by guidance around the use of AHEoL, an area that holds so much clinical and ethical uncertainty.

**Abstract number:** P1-037  
**Abstract type:** Poster

## Pain and Symptom Management in Patients with Multiple Myeloma Treated at an Integrated Palliative Care and Oncohematological Outpatient Clinic: First Year Experience

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**Background:** Few reports exist on the potential benefit of integrating palliative care with oncohematology.

**Aim:** To assess changes in pain and symptoms during the first 3 months of follow-up in patients (pts) with Multiple Myeloma (MM) treated at an Integrative Palliative Care and OncoHematological outpatient clinic (IPCOH).

**Methods:** Consecutive pts scheduled for a visit at the IPCOH were assessed at the 1<sup>st</sup>, 2<sup>nd</sup>, and 3<sup>rd</sup> visits and beyond (up to 90 days). Pain, asthenia, anorexia, constipation, insomnia, nausea/vomiting, dyspnoea, anxiety and depression were assessed using the Verbal Rating Scale (0-10). Pain interference with Sleep, General Activity, and Mood was recorded. Pain prognosis was assessed with the Edmonton Classification System-Cancer Pain. Analgesic use was also evaluated. Missing symptom data were managed with the Last Outcome Carried Forward strategy. Pain and symptoms were scored as none-mild ( $\leq 4$ ) and moderate-severe ( $> 5$ ). Changes in pain and symptoms from baseline were assessed with the Wilcoxon Signed Ranks Test.

**Results:** During the year 2013, 67 pts (33 women) were included. Mean age was 69 years. At the 1<sup>st</sup> visit, 84% pts had pain; of these, 87.5% had a poor pain prognosis. The percentage of pts with 'Worst pain'  $\leq 4$  at the 1<sup>st</sup> visit, 2<sup>nd</sup> (median 14 days), 3<sup>rd</sup> (median 21 days) and beyond the 3<sup>rd</sup> visit (median 60 days) was 43%, 55%, 61%, and 82%, respectively;  $P < 0.0001$ . The proportion of pts reporting pain interference improved from baseline, as follows: Sleep (27% vs. 9%;  $P = 0.01$ ), General Activity (46% vs. 12.5%;  $P < 0.001$ ) and Mood (46% vs. 18%;  $P < 0.001$ ). The median symptom load scores of physical ( $P = 0.03$ ) and emotional ( $P = 0.02$ ) symptoms improved over time. Basal strong opioids use increased from 55% to 78%;  $P < 0.0001$ .

**Conclusions:** Pain remains a major problem in pts with MM. Pain and other symptoms, both physical and emotional, improved during follow-up. Close collaboration between PC specialists and haematologists proved beneficial in our context.

**Abstract number:** P1-038

**Abstract type:** Poster

## O<sub>2</sub> or No<sub>2</sub> in Palliative Medicine?

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**Background:** Oxygen is frequently used in palliative care for dyspnoea. Traditionally oxygen may have been considered a benign therapy with few risks. However there are many potential side effects, not all of which are physical.

**Objective:** To evaluate if the use of oxygen for symptom control in palliative care is supported by the evidence.

**Method:** A working group examined the evidence surrounding the use of oxygen in palliative care. A literature search was conducted in March 2013 using NHS Evidence Healthcare Database. This searched AMED, EMBASE, HMC, Medline, PsychINFO, BNI, CINAHL, Health Business ELITE. Terms 'palliative' 'end of life' or 'terminal' were combined with 'oxygen' to search the title. The search was limited to full text and English language. All abstracts were analysed to exclude articles whose topic was not relevant to the literature review.

**Results:** There is no significant evidence that oxygen is more beneficial than air, although both give symptomatic relief of dyspnoea. Some studies show a small patient preference for oxygen, although this is not statistically significant.

Abernethy's trial in 2010 has addressed many of the limitations of previous trials including sample size, trial duration and patient-centred outcomes yet still found no additional benefit of oxygen over air in palliative patients.

**Conclusion:** The risk benefit ratio for the use of oxygen needs to be assessed on an individual patient basis against the disadvantages including social stigma, reduced mobility, patient safety and potential side effects.

**Abstract number:** P1-039

**Abstract type:** Poster

## Levetiracetam Use in Patients with Brain Tumours towards the End of Life: A Feasibility Study Preparatory to a Pharmacokinetic Study

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**Background:** Levetiracetam is increasingly prescribed as a first line anticonvulsant therapy for patients with brain tumours. The use of subcutaneous (SC) levetiracetam to manage seizures in the terminal phase (although unlicensed) has been described in case reports. We are planning a pharmacokinetic study to determine the bioavailability of SC levetiracetam. As part of the preparatory feasibility work we undertook a retrospective notes review.

**Aim:** To determine the frequency with which levetiracetam is used in patients with brain tumours approaching the end of life and the feasibility of undertaking a pharmacokinetic study.

**Methods:** A retrospective notes review of hospice patients with brain tumours who had died. Data were extracted to determine the proportion of patients whom had been on oral levetiracetam prior to entering the terminal phase. Information about their subsequent seizure management was also recorded.

**Results:** The notes of 26 patients with brain tumours who had died over a 12 month period were reviewed. 12/26 (46%) patients were on levetiracetam as they approached the terminal stage of their disease. When patients were unable to swallow, the majority (11/12; 92%) were switched to continuous SC midazolam infusions; 2/12 (17%) also required SC phenobarbital. Patients remained on SC anticonvulsant infusions for a median of 7 days prior to death.

**Conclusion:** Levetiracetam is commonly used in patients with brain tumours. In our planned pharmacokinetic study we aim to recruit patients (n = 6) with brain tumours who are on regular oral levetiracetam. When patients lose the ability to swallow medication they will be switched to SC levetiracetam with testing of their serum levetiracetam level after 48 hours. Our retrospective notes review suggests that if we recruit 50% of eligible patients and allow for 50% attrition then we can still expect to recruit the required sample size for our pharmacokinetic study in a single centre during a 12 month period.

**Abstract number:** P1-040

**Abstract type:** Poster

## The Current Practice of Palliative Sedation in Austria - A Nationwide, Multicentre Survey on Behalf of the AUPAC (Austrian Palliative Care) Study Group

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**Background:** Palliative Sedation (PS) is becoming an increasingly used practice in end-of-life-care. In clinical practice consensus about definitions, indications and treatment decision making is still difficult to achieve. To date the practice of PS in Austria has not properly been investigated.

**Methods:** This multicentre study presents a retrospective analysis of sedation-related data obtained at palliative care units and hospices from the Austrian Palliative Care (AUPAC) Study Group. Data on sedation were retrieved of all patients who died at an AUPAC unit between June 2012 and June 2013. Clinical characteristics and co-medications of sedated patients, indications, drugs used for PS and duration of PS in the last two weeks of life were recorded.

**Results:** In total 2424 cancer patients died at 23 AUPAC units, median age was 74 (range 20-104 years), 52% were female, 48% male. 20.8% (range 0-50%, n=503) received PS and 71% of all sedated patients deep continuous sedation. In 33% PS was given in the last 24 hours before death. Main indications for PS were delirium (51%), existential suffering (32%), dyspnea (30%) and pain (20%). Drugs used were midazolam (79%), lorazepam (13%) and haloperidol. There was no detectable difference in survival time between sedated and non-sedated patients. Sedated patients were significantly younger (p=.000\*), male (p=.014\*) and received significantly more often opioids (p=.000\*), deep venous thrombosis prophylaxes (p=.043\*) and artificial hydration (p=.001\*).

**Conclusion:** This study allows the first insight into prevalence, and decision-making of PS in

patients in Austria. Indication and treatment decisions vary widely across AUPACS institutions. To enhance safety in clinical practice, implementation of a nation-wide guideline for the use of PS will be developed.

**Abstract number:** P1-041

**Abstract type:** Poster

## Retrospective Study of Cases of Deceased Persons with Intellectual Disabilities: The Moment of Physicians' Recognition of People Nearing End-of-Life

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**Background:** Physicians for people with intellectual disabilities (ID) are increasingly confronted with patients in need of palliative care. However, early identification of those people with ID is difficult. Research on this topic is scarce, despite the fact that early recognition of palliative care needs is essential for providing optimal and proactive palliative care. Little is known about when and how physicians recognize people with ID nearing end-of-life.

**Aims:** In the present study we aim to describe when physicians recognise people with ID nearing end-of-life. Next to this we aim to describe determinants, such as signals and symptoms, of the moment physicians recognise people nearing end-of-life.

**Methods:** 97 ID physicians and General Practitioners filled in a comprehensive retrospective questionnaire about the process of palliative care provided to a deceased patient with ID. Hierarchical logistic regression analysis was used to examine determinants.

**Results:** Almost 25% of the physicians did not recognise patients with ID nearing end-of-life before the last week of life. Signals and symptoms on the moment of recognition of people nearing end-of-life vary greatly. Most reported signals that led to this recognition were changes in typical behavior of the patient, a decline in functioning and not responding to treatment or medication. Most reported symptoms were fatigue, drowsiness, decreased appetite and weight loss. Regression analysis show that the underlying illness is an important patient characteristic associated with the moment of recognition of people nearing end-of-life.

**Conclusion / Discussion:** The results show that in a significant amount of people with ID recognition of people nearing death happened late in the end-of-life phase. The diversity of signals and symptoms on the moment of recognition of people nearing end-of-life is great. Insight in end-of-life signals and symptoms can contribute to early identification of people in need for palliative care.

**Abstract number:** P1-042

**Abstract type:** Poster

## Pharmacological and Nonpharmacological Interventions for the Treatment of Chronic Cough in Patients with Interstitial Lung Disease: A Systematic Review

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**Introduction:** Chronic cough is cough lasting more than 8 weeks. It affects up to 80% of patients with Interstitial Lung Disease and is a major disruption in quality of life for patients due to the fact that it can produce loss of appetite, dizziness, vomiting, syncope, sweating, hoarseness, and overall exhaustion. The cause of cough in patients with ILD may be due to a diagnosis other than the underlying condition in at least 50-54% of the cases. This review sought to find available evidence on the treatment of cough that is directly related to ILD.

**Objective:** To determine the effectiveness of pharmacological and non-pharmacological interventions for the treatment of cough in ILD.

**Methods:** This is a limited systematic review. Search was performed on the databases MEDLINE, EMBASE, Cochrane, Web of Knowledge for all types of studies in which an intervention was evaluated and changes in cough pattern and quality of life were one of their outcomes.

**Results:** A total of 1271 references were screened and 11 papers were finally obtained for this review, three systematic reviews, three open-label studies, 4 RCT (three double blind parallel, one crossover) and one N-of-1 trial. Among the studied interventions were IFN, thalidomide, prednisolone, cotrimoxazole, fluticasone, tramadol, nebulized morphine, moguisteine, codeine, and levodropropizine. Even though the studies showed effectiveness for thalidomide, prednisolone, cotrimoxazole, tramadol, moguisteine and levodropropizine, sample size, selection bias and measurement bias diminish their possible effects on clinical practice.

**Conclusions:** A limited and heterogeneous amount of evidence is available. The results obtained offer limited but more promising information regarding treatment of cough in ILD but no evidence was found for treatment in end stage disease nor on the long-term effects of these medications. Higher level of evidence is needed in order to be able to apply these results into our clinical practice.

**Abstract number:** P1-043  
**Abstract type:** Poster

## Acute Bacterial Parotitis in the Dying Patient

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The clinical entity of acute bacterial parotitis (ABP), also known as acute suppurative parotitis, is an infection of rapid onset and is characterised by unilateral parotid gland swelling, localised erythema, intense pain and/or trismus. We describe two recent cases in adults in a specialist palliative care unit (SPCU).

Predisposing factors for ABP include advancing age, xerostomia, a debilitated patient and poor oral hygiene. The majority of dying patients manifest at least one of these factors. For example, a significant anti-muscarinic burden, reduced oral intake and the physiological toll of a terminal illness may all increase the risk of developing ABP. Some have even suggested the onset of ABP is a surrogate marker for imminent decline and death. Where it does occur, the significant pain, highly visible swelling and difficulty swallowing can cause great distress for both patient and relative. Prompt antibiotic therapy and other simple conservative measures are known to be an effective means of palliating these symptoms. As such, it is of significant relevance to palliative care and yet to our knowledge it has not been described in the palliative medicine literature.

Our poster reviews the predisposing factors, clinical course and treatment of ABP in the two cases at our SPCU. We also present a review of the literature regarding ABP and its management. We argue that the dying patient should be considered very high risk for its development. We advocate prompt recognition and treatment to reduce the impact of this distressing complication in the dying patient.

**Abstract number:** P1-044  
**Abstract type:** Poster

## Nutritional Supplement Use in Hospice Inpatients: Review of Prevalence and Rationale

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**Introduction:** Nutritional status declines in advanced disease. 'Nutritional supplement' encompasses complete and incomplete dietary supplements, vitamins and minerals. Although prescribed for malnutrition, limited guidance informs their use in palliative medicine.

### Aims:

1. Review the prevalence of nutritional supplement use in hospice inpatients
2. Document commonly prescribed supplements and routes of administration
3. Evaluate rationale for initiation and discontinuation
4. Review prevalence of appetite stimulant prescription

**Methods:** A retrospective medical record review of 102 consecutive deceased patients was conducted at a palliative medicine unit. A data recording form evaluated nutritional supplement use. Descriptive statistics were generated with Microsoft Excel.

**Results:** The studied cohort comprised 92 cancer and 10 non-cancer diagnoses. 42% (43/102) were prescribed a supplement, a third of whom were prescribed more than one. 14% (6/43) received supplements by enteral/parenteral routes. 86% (37/43) were administered orally. The majority were prescribed prior to admission, most commonly iron. 35% (15/43) started supplements during admission with Vitamin C most frequent (5/15). However, this was used for oral hygiene rather than nutrition. 49% (50/102) were prescribed steroids for multiple indications which may have had an appetite stimulant effect. Prescription and discontinuation rationales were recorded in less than half. In 43% (17/43) supplements were continued until the day of death.

### Conclusion:

1. Almost half received one or more oral supplements.
2. Supplement polypharmacy is a key issue.
3. Rationales were recorded in less than 50% of cases.
4. Vitamins and minerals were most used.
5. Future studies should focus on the impact of supplements and stimulants on appetite, weight and quality of life.

**Abstract number:** P1-045  
**Abstract type:** Poster

## Cancer-related Insomnia: Wireless Monitoring of Sleep Metrics

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**Background:** Insomnia is defined as difficulty with sleep onset, maintenance, early morning waking or non-restorative sleep. Prevalence is 30-75% in advanced cancer. Daytime consequences include fatigue and impaired memory/concentration. It is under-reported, overlooked and severely impairs quality of life. Subjective sleep diaries underestimate insomnia. Objective measurements previously required dedicated sleep laboratories. Wireless medical technology enables objective sleep measurement in the natural environment.

### Aims:

1. Conduct a feasibility study to examine if a wireless monitor can measure sleep in cancer
2. Evaluate user interface/acceptability in:
  - a. Patient
  - b. Nurse
3. Correlate device results with subjective sleep diary.

**Methods:** A prospective observational study recruited 10 consecutive cancer inpatient admissions to a hospice. Baseline Insomnia Severity Index recorded subjective sleep pattern. Participants used a wireless non-contact bedside sleep monitor (SleepMinder™) for 3 nights. A daily sleep diary was completed. Acceptability questionnaires were completed by both

patient and nurse. Descriptive statistics were generated with Microsoft Excel. Further evaluation in community ongoing.

**Results:** All 10 participants had metastatic cancer (lung [5]; gastrointestinal [4]; breast [1]). Median age was 63 years (range 47-61). Median Eastern Cooperative Oncology Group (ECOG) performance status was 2 (range 1-3). In 50%, sleep onset was delayed >30 minutes on 2 of 3 nights. Median sleep duration was 7.5 hours in the diary vs. 8 on the device. Both diary and device recorded a median of 1 awakening per night (range 0-8). Median sleep efficiency (proportion of time in bed spent asleep) was 89% (range 74-100%). Participants and nurses reported 100% device acceptability.

### Conclusion:

1. A wireless bedside monitor effectively measures sleep in cancer.
2. 100% patient and nurse acceptability supports clinical use.
3. Research in progress to evaluate device use at home.

**Abstract number:** P1-046  
**Abstract type:** Poster

## Large Volume Paracentesis versus Tunnelled Drainage Catheters for the Management of Malignant Ascites in Adults: A Systematic Review of the Literature

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**Background:** Development of malignant ascites causes significant morbidity for patients with cancer. Drainage of ascites can offer symptomatic benefits, but practice is variable with regard to choice of device, duration and frequency of drainage.

**Aims:** To appraise the evidence for abdominal paracentesis in adults with malignant ascites, including a comparison of large volume paracentesis (LVP) versus tunnelled drainage (TD).

**Methods:** A systematic literature review was conducted to identify relevant studies. Full texts of 30 papers were reviewed and 16 were included in the analysis.

**Results:** Using the SIGN criteria 15 studies were graded evidence level '3' and one study level '2'. Symptoms improved in 78-100% following LVP and 65-100% following TD. Complication rates (including infection, intestinal perforation and failure) were reported at a lower frequency in patients undergoing LVP compared to TD (4.4% vs 18.3%). Eight deaths occurred in 1180 LVP procedures (four hypotension, two pulmonary emboli, one bowel perforation and one purulent peritonitis); there were no deaths with insertion of 388 TDs.

**Conclusions:** Overall quality of evidence is low, but use of LVP may be more effective with regard to alleviating symptoms compared to TD and is associated with lower morbidity but higher mortality. Decisions regarding ascitic drainage should take into account potential benefits and burdens of different treatments, performance status, risk of hypotension, preferred place of care, and estimated prognosis.

**Abstract number:** P1-047  
**Abstract type:** Poster

## Mood Stabilizers and Patients with Advanced Illness- A Forgotten Tool?

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**Aims:** Patients with advanced illness frequently experience a high symptom burden both physical and psychological including depression and anxiety. While mood stabilisers are of proven benefit in psychiatric illness, there is little known about the frequency of their use in patients under specialist palliative care. However given the goal of optimising quality of life, effective treatment of mood disorders is important for holistic patient care. The aim is to assess the frequency of use of mood stabilisers in patients under a specialist palliative care homecare team.

**Methods:** A cross-sectional, retrospective, chart review was performed on all existing adult patients under a rural, specialist palliative care homecare team, including referrals on the day of the study. Verbal consent was sought. Patients were excluded if they were very ill or imminently dying. Patient identification was coded. Demographics assessed included age, gender, diagnosis, pre-existing psychiatric illness and medications. The use of anxiolytics, mood stabilisers, antidepressants, antiepileptic and neuropathic agents was recorded. The results were analysed by descriptive analysis.

**Results:** 94 patient charts were eligible for inclusion. 85 patients had malignancies. 17 patients had a pre-morbid psychiatric diagnosis. 31 patients were on antidepressants, one on lithium, 3 on carbamazepine. While 15 received regular anxiolytics, 10 as required anxiolytics.

**Conclusion:** Only 4 patients received mood stabilisers despite 48.9% of patients receiving either antidepressants or regular anxiolytics. The use of anxiolytics used for the palliation of dyspnoea may be a confounder. Similarly patients on neuropathic agents may be experiencing a therapeutic mood effect. Nonetheless, mood stabilisers were infrequently used. More research is necessary to determine the possible benefits to patients with advanced, life threatening illness from mood stabilisers with the aim of optimising symptom control and quality of life.



# Poster Sessions (Poster Exhibition Set 1)

**Abstract number:** P1-048

**Abstract type:** Poster

## Rating Delirium Severity Using the Nursing Delirium Screening Scale: A Prospective Study

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**Background:** Delirium is a frequent neuropsychiatric complication in palliative care (PC). The Nursing Delirium Screening Scale (Nu-DESC) is a brief, 5-item, observational tool. It has face validity for severity rating, but has not been validated for this purpose in a PC setting.

**Aim:** To assess the validity of the Nu-DESC as a delirium severity rating tool for PC inpatients.

**Methods:** We conducted a prospective, observational study on a 31-bed, inpatient PC unit. Consecutive patients admitted to the PC unit were approached for preemptive informed consent. Patients were excluded if they had delirium on admission, were unable to converse in English, or had a Palliative Performance Scale (PPS) of  $\leq 10\%$ . Nu-DESC ratings were made at the end of each 8-hour nursing shift. Upon delirium diagnosis, as confirmed by the Confusion Assessment Method, the attending physician conducted a Clinician's Global Rating (CGR) of delirium severity; and a study investigator (blinded to CGR and Nu-DESC scores) conducted a Memorial Delirium Assessment Scale (MDAS) rating. Pearson correlation coefficients were calculated for Nu-DESC and MDAS scores.

**Results:** Of 564 patients screened, 139 were eligible and consented, and 46 developed incident delirium and remained eligible for primary analysis. Mean age was 73 years (range 36-96); 93% had cancer; and median PPS score was 30%. Pearson correlations between MDAS and Nu-DESC average and maximum scores were 0.42 ( $p=0.005$ ) and 0.41 ( $p=0.006$ ), respectively. CGR's for delirium were mild (43%), moderate (48%), and severe (9%). Delirium subtypes per MDAS assessments were normal psychomotor activity (9%), hypoactive (72%), hyperactive (4%), and mixed (15%).

**Conclusions:** Based on moderate correlation with MDAS scores, our study demonstrated concurrent validity of the Nu-DESC as a delirium severity rating tool. When a precise measure of delirium severity is required, a more specific tool should be considered.

**Abstract number:** P1-049

**Abstract type:** Poster

## Standard Operating Procedures in Palliative Care for Somatic and Psychiatric Symptom Management - A Pilot Assessment of Possible Application in Other Departments

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**Background:** Treatment of patients in a palliative care situation should be based both on existing evidence and clinical experience. Many specialties have developed standards to improve therapy and create awareness in members of other specialties. For our department standard operating procedures for the symptom oriented treatment of dyspnea, pain, anorexia and nausea were defined and implemented in 2014. It is unknown, whether a transfer of the SOP established in our palliative care clinic into other specialties that care for patients in a palliative care situation is feasible and accepted by other disciplines.

**Method:** SOP were presented to and analysed by health care experts in other departments (residents and attending physicians, neurology and internal medicine,  $n=11$ ) and asked to answer the questions: a. would the SOP be feasible, b. would they be effective, c. would you implement them, d. do you find them helpful. Answers were given on a Likert scale from 0=not at all to 3=fully and were dichotomised (0, 1 = negative reaction and 2, 3 = positive reaction).

**Results:** All of the health care specialists ( $n=11$ ) in other departments expect the SOPs both to be feasible as well as effective. Most of the health care specialists in other departments thought they would implement the SOPs for palliative care patients (90,1%;  $n=10$ ) and they would be helpful in their work with palliative patients (72,7%,  $n=8$ , reasons for negative reaction was: specific medication as in SOP not available on ward,  $n=2$ , no answer given,  $n=1$ ).

**Conclusion:** The pilot assessment shows that the proposed SOP may be transferred into routine treatment of other specialties, thus (i) fostering better symptom oriented treatment of patients with palliative care needs in non-palliative departments, (ii) establishing an awareness for palliative care needs and possible treatments and (iii) alleviating working with palliative patients for medical doctors of other specialties. More research is needed.

**Abstract number:** P1-050

**Abstract type:** Poster

## A Protocol for the Control of Agitation in Palliative Care

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**Background:** Agitation occurs frequently in palliative care and is one of the most important reasons for sedation. Agitation can have many causes and can be reversible, but when it occurs can be very distressing for all involved.

**Aim:** To study the effectiveness of a protocol development in our service for the control of agitation.

**Methods:** The protocol was activated in 18/06/2007, which was the date of the opening of

our palliative care unit (PCU) and all patients were included in the study until 31/12/2013.

**Protocol for the control of agitation:**

- Haloperidol - 5mg IM + Midazolam - 5 mg IM

30 minutes later, if the situation is not controlled:

- Haloperidol - 2 mg SC + Midazolam - 5 mg SC; up to 2 doses (30 minutes interval)

30 minutes later, if the situation is not controlled:

- Midazolam 5 mg SC every hour till the control of the situation. If the agitation recurs:

- Less than 2 hours after control: resume the protocol from the interruption point.

- More than 2 hours later: restart the protocol from the beginning.

**Results:** During the period in study 1558 were admitted and the protocol was used in 135 (9%). 102 (76%) were males and the mean age was 65.75 years ( $SD \pm 12.09$ ). The most frequent diagnosis was head and neck cancer, 37 (27%), followed by lung cancer, 27 (20%). The protocol was used correctly 584 times, from 1 to 31 times in each patient, median 3 times. The interval between the first dose and the control of agitation was from 1 to 105 minutes, median 14 minutes. 534 (91%) of the agitation episodes were controlled with only the first dose of the protocol. There were any treatment complications.

**Conclusion:** The protocol for the control of agitation developed in our PCU is very effective as demonstrated by the quick control of the situation, usually with only one dose, and the lack of complications.

**Abstract number:** P1-051

**Abstract type:** Poster

## Efficacy of Percutaneous Trans-esophageal Gastro-tubing as Palliative Care for Patients with Gastrointestinal Obstruction: 20 Years' Experience

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**Background:** In 1994, we devised percutaneous trans-esophageal gastro-tubing (PTEG) for a patient with gastrointestinal obstruction due to carcinomatosis because bowel adhesions prevented us from performing percutaneous endoscopic gastrostomy. PTEG proved to be very effective not only for drainage but also for feeding, so it is now often used for enteral nutrition. Since 1994, PTEG has been performed in approximately 20,000 patients in Japan.

**Aims:** We wished to determine the efficacy of PTEG for palliative care of patients with gastrointestinal obstruction due to carcinomatosis from our 20 years' experience.

**Methods:** We reviewed the cases of all 297 patients that we have treated by PTEG from 1994 to 2014, including 121 patients (40.74%) for drainage and 176 patients (59.26%) for feeding. The drainage by PTEG was a principal part of palliative care for 110 patients suffering carcinomatosis due to gastric carcinoma ( $n=59$ , 53.64%), colorectal carcinoma  $n=21$ , 19.09%, ovarian carcinoma ( $n=9$ ; 8.18%), pancreatic carcinoma ( $n=6$ , 5.45%), bile duct carcinoma ( $n=6$ , 5.45%), esophageal carcinoma ( $n=3$ , 2.73%), and others ( $n=6$ , 5.45%). We examined the principal short-term outcomes of PTEG in these 110 cases.

**Results:** PTEG provided relief from the discomfort and diminished quality of life (QOL) resulting from use of a nasogastric tube. In all patients, digestive juice was effectively drained via the indwelling PTEG tube, and there was no nausea or vomiting. After the PTEG procedure, patients could once again enjoy the taste of drink and of foods that melt in the mouth. Patients became suitable candidates for home care and/or chemotherapy.

**Conclusion:** PTEG is a simple, minimally invasive means of improving a patient's QOL both easily and effectively. We recommend PTEG as the procedure of choice in the palliative care of patients suffering gastrointestinal obstruction due to carcinomatosis.

**Abstract number:** P1-052

**Abstract type:** Poster

## Malignant Intestinal Obstruction - Management and Ethical Dilemmas in Palliative Medicine

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**Introduction:** Treatment of patients with intestinal obstruction in terminal stadium of malignant disease, being admitted in hospice, has been a challenge, by which the doctors face with in palliative medicine. Malignant intestinal obstruction has been a frequent complication in patients with an advanced cancer in the abdomen and the small pelvis.

**Material and method:** A total of 165 patients were treated in the Hospice Sue Ryder in Skopje, within the years 2005 to 2010. All they were in terminal stadium of the disease: 86 of them had colon carcinoma, 22 stomach carcinoma, 19 genital carcinoma, 10 patients had pancreas carcinoma, the rest of them had metastatic changes of other locations.

**Results:** Of the total number of patients, 57 were referred to surgical treatment, the others were treated conservatively. Of the patients who were referred to surgical treatment, only seven patients survived more than 60 days after the surgery, but intermittent symptoms of incomplete or complete intestinal obstruction reoccurred in four of them. Complications such as infection and wound dehiscence, sepsis, enterocutaneous fistula, bleeding, and pulmonary embolism developed in 19 of the operated patients. Of conservatively treated patients, 53 were cured with proximal decompression - nasogastric probe, two with PEG, while the others with a drug therapy - antiemetic, antisecretolytic, anti-inflammatory drugs, only one patient administered octreotide.

**Conclusion:** Recommendations for conservative versus surgical treatment in patients having advanced cancer are still controversial. Selection of patients for surgical treatment has to be based on complete evaluation of the patients' condition, advancement of the disease, expected time of survival as well as of the quality of life in the remaining period. This decision has to be based on multidisciplinary approach between the doctor in the hospice, surgeon, oncologist as well on the decision of the patient and his family.



**Abstract number:** P1-053

**Abstract type:** Poster

## Genetic Variations and Cognitive Dysfunction in Opioid Treated Patients with Cancer

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**Background:** The effects of single nucleotide polymorphisms (SNPs) in the cognitive function of opioid treated patients with cancer is unknown.

**Aim:** To identify associations between SNPs of candidate genes, high opioid dose and cognitive dysfunction.

**Methods:** Cross-sectional multicenter study (European Pharmacogenetic Opioid Study, 2005-2008), in which 1586 patients were analysed regarding 86 SNPs in 43 genes. Inclusion criteria: cancer, age  $\geq 18$  y, regular opioid treatment for  $\geq 3$ d, and available genetic data. Cognitive function was assessed by Mini Mental State Examination (MMSE). Analyses: 1) SNPs were rejected if evidence of violation of Hardy-Weinberg equilibrium ( $P < 0.0005$ ), or minor allele frequency  $< 5\%$ ;

2) patients were randomly divided into development sample (2/3 patients for initial SNPs screening) and the validation sample (1/3 patients for confirmatory test); 3) a false discovery rate of 10% was used for determining associations (Benjamini-Hochberg method).

Kruskal-Wallis test (co-dominant model) and the Mann-Whitney test (dominant and recessive models) were performed.

**Results:** Significant associations ( $P < 0.05$ ) between MMSE scores and SNPs in the genes *HTF3E*, *TACR1*, and *IL6* were observed in the development sample, but the replication in the validation sample did not confirm it. Associations between MMSE scores among patients receiving  $\geq 400$ mg morphine equivalent dose/day ( $n=377$ ) and SNPs in *TNFRSF1B*, *TLR5*, *HTF2A*, and *ADRA2A* were also observed in the development sample, but could not be confirmed in the validation sample. After correction for multiple testing, no SNPs were significant in the development sample. Significant associations with other SNPs were observed when applying dominant and recessive models, but could not be confirmed after correction for multiple testing or replication in the validation sample.

**Conclusion:** The findings did not support influence of those SNPs analysed to explain cognitive dysfunction in this sample of patients.

**Abstract number:** P1-054

**Abstract type:** Poster

## Effect of Shitei-To, a Traditional Chinese Medicine Formulation, against Hiccups - Effect of Shitei Extract on Drug-induced Convulsions in Mice

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**Introduction:** Cancer patients sometimes have hiccups for the enforcement of chemotherapy or the tumor itself. Hiccups, which are rhythmical, clonic contractions of the diaphragm, are considered as a form of convulsions. For a treatment of intractable hiccups, a number of major tranquiliser or anticonvulsant medications such as benzodiazepine or barbiturate have been used. The traditional Chinese medicine Shitei-To, which is a mixture of extracts from three medicinal herbs, Shitei (Persimmon; Kaki Calyx; calyx of *Diospyros kaki* L.f.), Shokyo (Zinger; Zingiberis rhizome; rhizome of *Zingiber officinale* Roscoe) and Choji (Clove; Caryophylli flos; flower-bud of *Syzygium aromaticum* [L.] Merrill et. Perry) has long been used for the treatment of hiccups as natural herbal therapy in Japan and China. Shitei-To might be effective against convulsions since the anticonvulsants are effective against intractable hiccups. In this study, we examined the anticonvulsant effect of Shitei-To and Shitei extract on experimental convulsion models, chemically induced convulsions (strychnine and picrotoxin) in mice.

**Methods:** The animals (6-week-old male ddY mice) were pretreated Shitei-To, Shitei water extract, Shitei methanol extract and Shitei ethyl acetate extract (p.o.) at a specified time prior to injection of strychnine and picrotoxin (i.p.). In these experiments, the latency to clonic convulsions was measured and recorded in seconds from the beginning of injection of convulsant to the appearance of clonic convulsions.

**Results and discussion:** Shitei-To and Shitei significantly prolonged the latency to strychnine and picrotoxin-induced clonic convulsions. Furthermore, Shitei extract also prolonged the latency to strychnine and picrotoxin-induced clonic convulsions. These findings suggest that Shitei-To has anticonvulsant effects.

**Abstract number:** P1-055

**Abstract type:** Poster

## Bowel Obstruction In Cancer Patients

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**Background:** Bowel obstruction is relatively frequent in some types of cancer. When it occurs in advanced cancer it is a sign of bad prognosis.

**Aim:** To study what happened to patients with a diagnosis of bowel obstruction in an oncological center.

**Methods:** Revision of the records of patients with a diagnosis of bowel obstruction during a 6 month period (January to June 2013).

**Results:** During the period under study 106 patients had a diagnosis of bowel obstruction. 67 (63%) were female and the median age was 66 years (22 to 100). The most frequent cancers were: colorectal, 39 (37%); gynecological, 23 (22%); and gastric 16 (15%). The most frequent metastases were: peritoneal, 48 (45%); hepatic, 34 (32%); and 26 (25%) were locally advanced. Previous treatments undergone by patients directed to cancer were: surgery 75 (71%), 72 of them were abdominal; chemotherapy 72 (68%); and radiotherapy 30 (28%). In 95 (90%) the bowel obstruction has resolved. In 40 (38%) there was an intervention: 7 (18%) with stent placement; and 33 (82%) surgery. 66 (62%) patients underwent conservative treatment. In all patients who had a stent placement the obstruction has resolved. 31 (94%) out of 33 who have undergone surgery had the obstruction resolved vs. 57 (86%) out of 66 who had a conservative management ( $p = 0.327$ ). 77 (73%) patients were discharged home and 29 (27%) died in hospital. 28 (26%) patients were referred to palliative care: 17 (59%) out of 29 who have died and 11 (14%) out of 77 who were discharged ( $p < 0.001$ ).

**Conclusion:** Bowel obstruction occurs more frequently in abdominal cancers such as the digestive and gynecological ones. Most of the episodes of obstruction resolved with conservative measures. When indicated the placement of a stent may be very effective. Only a minority of the patients were referred to palliative care mainly those with the poorest condition, as most of them died in the sequence of the episode of bowel obstruction.

**Abstract number:** P1-056

**Abstract type:** Poster

## The Use of Antibiotics in Palliative Care: An Exploratory Study

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**Background:** Frail patients are vulnerable to infections and the decision to treat those infections may be difficult and must be individualised.

**Aim:** To survey the use of antibiotics in a palliative care unit.

**Methods:** Review of the records of patients who have been treated with antibiotics between July 2009 and December 2011.

**Results:** In the period under study antibiotics were used in 181 patients 291 times. 110 (61%) were male. The mean age was 64.14 years (SD  $\pm 13.65$ ). Only 7 (4%) were non-oncological patients. The most common oncological diagnoses were colorectal cancer 35 (20%), head and neck 33 (19%), lung 27 (15%) and brain 18 (10%). The number of episodes of antibiotic use varied from 1 to 10; 52 (29%) were infected at the admission. The most common source of infection was the respiratory tract, followed by tract urinary and skin. In 105 positive bacteriological analyses *S. aureus* (21%) was the most frequent isolated bacteria, followed by *K. pneumoniae* (19%), and *E. coli* (18%) and *P. aeruginosa* (17%). The most used antibiotic was amoxicillin clavulanate, followed by ciprofloxacin and cotrimoxazol. In 76% parenteral routes were used. Many patients had additional risk factors for infections such as: indwelling catheter - 77 (43%); pressure ulcers - 67 (37%); nasogastric tube - 38 (21%); neoplastic wound - 34 (19%); tracheostomy - 24 (13%).

**Conclusion:** The importance that infections may have in patients with far advanced diseases is the impact that they may have in their well-being or the foul-smelling that they may cause. In some situations, however, the use of antibiotics may be futile and may even interfere and prolong the dying process. More research in this area should be carried out allowing the eventual development of guidelines to help the process of decision which may be complex.

**Abstract number:** P1-057

**Abstract type:** Poster

## Quality of Life Assessment of Subcutaneous Needle Drainage for Lymphoedema in Patients with Advanced Malignancy

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Patients with advanced malignancy commonly develop lymphoedema of the lower limbs. This can have a profound impact on quality of life (QOL). Standard therapy for lymphoedema includes massage, bandaging and compression hosiery, but this can be of limited effect at the end of life. Draining the fluid through the placement of needles under the skin is a technique mentioned sporadically in the literature. It has been shown, in small studies, to be of benefit for symptom control; however it is not clear how it affects QOL and if there are any negative outcomes.

The aim of this pilot study was to use objective tools to measure quality of life and function of patients with severe lymphoedema before and after subcutaneous needle drainage. It also captured data on complication rates. A protocol was developed locally for the procedure. The LymphQOL questionnaire was used before, immediately following and 3 weeks after the drain. It tested several domains including activities of daily living, appearance, and symptoms. A functional measure was utilised to capture changes in the patient's important activities.

The pilot included 10 patients. The volumes of lymphoedema drained ranged between 102mls and 12,670mls. One patient did not drain at all. Of the remaining nine participants, all but one showed improvements in their scores in at least one domain. Seven of the patients improved in appearance and five had positive outcomes with their own mobility measures. Two of the patients developed cellulitis managed with oral antibiotics. This pilot showed promising results for patients with severe, refractory lower limb lymphoedema when standard therapy is no longer an option. It appears to be a safe intervention with positive results for the majority of patients. It is the first study using objective measures in the literature. However, it is a small study in one centre of New Zealand and warrants further research.

This study was funded by the Campbell Ballantyne Fellowship.

**Abstract number:** P1-058  
**Abstract type:** Poster

## Gastrointestinal Adverse Events during Naloxegol Treatment for Opioid-induced Constipation: Evidence from Double-Blind RCTs

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**Background:** Opioid induced constipation (OIC) is a serious and frequent adverse event. Naloxegol, a recently approved oral, peripherally acting  $\mu$ -opioid receptor antagonist (PAMORA), has been shown to be effective in OIC treatment.  
**Aim:** The objective was to analyse the incidence of naloxegol-related gastrointestinal (GI) adverse events (AEs) in adult OIC patients.  
**Methods:** The results presented are part of a systematic review. Five databases including MEDLINE, PubMed, Cochrane (CENTRAL) and EMBASE were searched in August 2014. Studies were screened independently by two reviewers for randomised controlled trials (RCTs). Risk differences (RDs) with 95%-confidence intervals (95% CI) were calculated using RevMan 5.3 (Mantel-Haenszel; fixed effect model).  
**Results:** One phase II and two phase III RCTs were identified, studying a total of 985 patients treated with naloxegol and 540 with placebo. Abdominal pain, nausea and diarrhea were the most frequently observed AEs and their incidence tended to increase with higher doses (see Table). Daily doses of 12.5mg caused noticeably less abdominal pain than higher doses. RDs were highest for abdominal pain (RD 0.08 [0.05-0.11]) and comparable for nausea (0.03 [0.01-0.06]) and diarrhea (0.04 [0.02-0.07]).  
**Conclusions:** The overall risk for GI AEs during treatment with naloxegol is low; the most frequent AE is abdominal pain, which likely represents a pharmacological effect of the PAMORA. The data suggest that dose titration may be useful to achieve the optimal balance between efficacy and AEs.  
**Funding:** None

Naloxegol: patients per group; dosing	Abdominal pain: n, (%) RD (95%-CI)	Nausea: n, (%) RD	Diarrhea: n, (%) RD	Study
PBO: 213; IG1: 211, 12.5mg, qd; IG2: 214, 25mg, qd	PBO: 7 (3.3); IG1: 18 (8.5); IG2: 27 (12.6); RD: 0.07	PBO: 10 (4.7); IG1: 15 (7.1); IG2: 16 (7.5); RD: 0.03 (-0.01-0.06)	PBO: 9 (4.2); IG1: 7 (3.3); IG2: 20 (9.3); RD: 0.02 (-0.01-0.06)	Chey et al. (2014), study 04
PBO: 231; IG1: 230, 12.5mg, qd; IG2: 232, 25mg, qd	PBO: 18 (7.8); IG1: 25 (10.9); IG2: 44 (19.0); RD: 0.07 (0.02-0.12)	PBO: 10 (4.3); IG1: 14 (6.1); IG2: 20 (8.6); RD: 0.03 (-0.01-0.07)	PBO: 10 (4.3); IG1: 18 (7.8); IG2: 21 (9.1); RD: 0.04 (0.00-0.08)	Chey et al. (2014), study 05
O-PBO: 96; IG1: 33, 5mg, qd; IG2: 30, 25mg, qd; IG3: 35, 50mg, qd	O-PBO: 3 (3.1); IG1: 1 (3.0); IG2: 9 (30.0); IG3: 6 (17.1); RD: 0.13 (0.05-0.21)	O-PBO: 9 (9.4); IG1: 5 (15.2); IG2: 4 (13.3); IG3: 7 (20.0); RD: 0.07 (-0.02-0.16)	O-PBO: 8 (8.3); IG1: 5 (15.2); IG2: 4 (13.3); IG3: 11 (31.4); RD: 0.12 (0.02-0.22)	Webster et al. (2013)
RD total (95%-CI)	RD: 0.08 (0.05-0.11)*	RD: 0.03 (0.01-0.06)*	RD: 0.04 (0.02-0.07)*	

[Most frequent gastrointestinal adverse events]

Table legend: IG: intervention group; O: overall; PBO: placebo; OIC: opioid-induced constipation; qd: every day; RD: risk difference; \* p<0.01 for overall effect; RD>0 favors placebo

**Abstract number:** P1-059  
**Abstract type:** Poster

## Symptom Prevalence, Palliative Care Needs and Quality of Life in Multiple Myeloma - A Multicentre, Cross-sectional Study

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**Background:** Multiple myeloma remains an incurable cancer with evidence that patients suffer more symptoms than in other haematological conditions. Palliative care services are rarely involved.  
**Aim:** To assess symptom prevalence, symptom severity, quality of life and palliative care needs in patients with multiple myeloma and to determine which factors are associated with higher symptom burden and poor QOL.  
**Method:** This multicentre, cross-sectional study included patients with multiple myeloma at all disease stages. The EORTC QLQ-C30, EORTC-MY24 and the Myeloma Patient Outcome Scale (MyPOS) were used to quantify HRQOL and palliative care needs. Point prevalence of symptoms and concerns at time of the survey was determined. Hierarchical regression and path analysis were used.  
**Results:** 555 patients with multiple myeloma with a median age of 69 years (range: 34-92) and on average 2.5 years post-diagnosis participated. 18.2% were newly diagnosed, 47.9% had stable disease and 32.7% had relapsed disease or were in the advanced, palliative phase of illness. Patients reported a mean of 5.1 (SD=2.7) symptoms. Over 70% had pain, 88.7% fatigue and 61.1% breathlessness. The most burdensome symptoms in the advanced stages were fatigue, poor mobility, pain, and tingling in the hand/feet. A positive correlation between disease severity and number of symptoms was found (r=0.21, p<0.001). Performance status ( $\beta$ = -0.24; p<0.0005), disease type (Light chain disease versus Immunoglobulin G or A) and type of treatments (stem cell transplant versus chemotherapy) had a significant direct relationship with HRQOL.  
**Conclusion:** Burden of symptoms in multiple myeloma is high, especially in the advanced stages of disease. Those receiving more toxic treatments and with light chain disease are at increased risk for poor HRQOL and should be considered for early referral to palliative care services.  
**Funding:** Myeloma UK, St Christopher's Hospice, National Institute of Health Research

**Abstract number:** P1-060  
**Abstract type:** Poster

## A Questionnaire Survey of Physicians and Nurses Regarding Constipation in Palliative Care Patients

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**Introduction:** The aim of the study was the assessment of the methods used for a diagnosis and treatment of constipation among surveyed physicians and nurses taking into account the efficacy of several drugs and respondents' knowledge of constipation management guidelines of the Polish Association for Palliative Medicine.  
**Methods:** A total of 217 respondents including 149 nurses and 68 physicians from home care services, palliative care units, out-patient palliative medicine clinics, mainly from two provinces (Wielkopolska and Kujawsko - Pomorskie) were administered a 20 questions survey regarding causes, diagnosis and treatment of constipation.  
**Results:** The surveyed met in clinical practice on average 7 patients with constipation during 7 days. The majority of surveyed devoted on average 4 h for the treatment of constipation. Both nurses and physicians for the diagnosis of constipation most frequently used the time since the last bowel movement (84% nurses, 76% physicians) and symptoms reported by patients (85% nurses, 93% physicians). Among constipation causes the surveyed listed mainly drugs (92% nurses, 96% physicians) and opioids were judged as drugs having the biggest impact on constipation appearance (96% for both groups). The treatment consisted mainly of oral laxatives (86% nurses, 95% physicians) usually in combination with rectal measures (85%) and diet recommendations (81% nurses, 91% physicians). For the question of the knowledge of recommendations of the Polish Association for Palliative Medicine regarding constipation management (elaborated in 2009) 208 surveyed responded: 143 (69%) positively and 65 (31%) negatively.  
**Conclusions:** The responses obtained indicate for the necessity of a continuous staff education and elaboration of updated constipation management guidelines in palliative care patients. These guidelines were recently published by the Expert Group of the Polish Association for Palliative Medicine.

## Assessment and measurement tools

**Abstract number:** P1-061  
**Abstract type:** Poster

## Review of Procedures for Management of Symptomatic Malignant Ascites in Palliative Care Patients from the Instituto Nacional del Cancer (National Institute of Cancer), Santiago de Chile

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**Introduction:** Malignant ascites (AM) is a sign of peritoneal carcinomatosis, which occurs in about 50% of patients with peritoneal dissemination of the primary tumor, being considered a sign of poor prognosis. According to the literature, the most common procedure is the paracentesis (98%) and has proven to be the most effective.  
**Method:** We reviewed the records of procedures to drain the AM, between May and December 2012.  
**Results:** The records of 34 procedures performed in 14 patients were analysed. In 64% it takes more than one procedure. The most common diagnosis is colon cancer (21.4%), followed by ovarian cancer, gall bladder and unknown primary origin cancer (14.3% respectively). The average time between diagnosis and first relief procedure is 511.9 days and AM regarding admission to Palliative Care Unit is 370.4 days. Among the patients who died at the time of analysis (50%) survival from the first procedure was 67.1 days, and in this subgroup the procedure was performed at 213.5 days from diagnosis, whereas among surviving patients, survival from the first method is 120.5 days at the time of review, and in this subgroup the procedure was performed at 810.1 days from diagnosis. Regarding procedures, 55.9% were evacuating paracentesis and 41.2% continuous peritoneal drainage installation. The main indication for the procedure was abdominal distension (64.0%), followed by abdominal pain (16.0%), dyspnea (12.0%) and anorexia (8.0%). Complications occurred in 23.5% of cases. No cases of peritonitis or hemorrhage was recorded. No patient died within 30 days of procedure.  
**Conclusion:** Analysis of the records shows the procedures of isolated peritoneal drainage (paracentesis) or continuous were effective and safe in this group of patients, with few complications and low severity. It is presented as a late phenomenon in neoplastic disease patients, highlighting that those with AM in earlier forms present worse prognosis, therefore it deserves a more profound analysis.

**Abstract number:** P1-062  
**Abstract type:** Poster

## Factors Influencing Uptake of a Comprehensive, Evidence-based, Carer Support Needs Assessment Tool in Palliative Home Care

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**Background:** The Carer Support Needs Assessment Tool (CSNAT) is an evidence-based tool for carer assessment and support. Successful implementation of the CSNAT requires a change from existing practitioner led approaches to carer assessment to one which is facilitated by the practitioner, but led by the carer.

**Aims:** To identify factors which facilitate or hinder uptake of the CSNAT into practice.

**Methods:** The CSNAT was implemented in 6 palliative home care services. Qualitative data were collected via interviews (9 practitioner 'champions', 6 managers), 2 focus groups and 3 workshops. All were recorded, transcribed and analysed thematically.

**Results:** Uptake of the CSNAT varied between services and practitioners and was influenced by the receptivity of the context into which it was introduced, in particular the:

- 'Organisational preparedness' (e.g. existing administration systems, working patterns, competing demands).

- 'Individual preparedness' (e.g. the extent to which practitioners understood the underlying tenets of the CSNAT and whether they felt it could bring about benefits).

Additionally, facilitation to support implementation of the CSNAT was key, this included:

- 'Internal facilitation' within the service (e.g. clear organisation steer, support for a CSNAT 'champion', discussion at meetings).

- 'External facilitation' from the research team (e.g. provision of training, reference materials, on-going support for champions).

**Conclusions:** The study identified two main factors which influence effective implementation of the CSNAT: a) receptivity of the context (both at organisational and individual level) and b) level of facilitation (within or outside the organisation). Findings correspond with theory and practice models of sustainable implementation of practice developments. Further work is underway to explore how organisations can best be supported during CSNAT implementation.

**Funder:** NIHR Research for Patient Benefit

**Abstract number:** P1-063  
**Abstract type:** Poster

## A Psychometric Approximation to the Spanish Version of Bugen's Coping with Death Scale

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**Background:** Working in a death context on a regular basis can have adverse effects for palliative care professionals. As a professional competence, coping with death has been defined as professional's abilities and skills to cope with death, and also his/her beliefs and attitudes towards these abilities. Among the instruments used to assess professionals' ability to cope with death, Bugen's Coping with Death Scale is one of the most employed.

**Aims:** To study the psychometric properties of the Coping with Death Scale in a nationwide sample of palliative care professionals.

**Design, methods and approach taken:** Through an on-line survey, palliative care professionals from all over Spain were invited to participate. 385 of the respondents met the inclusion criteria. Among other variables, coping with death competence was assessed using Bugen's Coping with Death Scale. Two confirmatory factor analyses for studying factorial validity were estimated and tested.

**Results:** As the first CFA showed bad psychometric behavior for 4 items of the scale. These items were removed and a second CFA was estimated and tested, with better results ( $\chi^2(299) = 1305.41$ ,  $\chi^2/df = 4.36$ , CFI = .93, and RMSEA = .10 (90% confidence interval = .09-.11). Based on this latest version of the scale, descriptive analyses for the palliative care professionals were offered.

**Conclusions:** Results for Bugen's Coping with Death Scale support previous exploratory studies. Same items behaving badly are identified. The short version shows clearly improved psychometric properties for the Spanish context. Descriptive analyses pointed appropriate levels of coping with death in Spanish palliative care professionals.

**Main sources:** This research was partially founded by the Spanish Association for Palliative Care (SECPAL).

**Abstract number:** P1-064  
**Abstract type:** Poster

## Pioneering Research on Demoralization in Spanish Palliative Care Units

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**Background:** Demoralisation is experienced when someone feels deprived of spirit, disheartened, and confused. Clarke and Kissane proposed a checklist for a demoralisation diagnosis (existential anguish/distress, pessimist cognitive attitudes, helplessness, absence of coping motivation, social isolation and emotional intensity fluctuation). Literature reveals that, in some cases, depressive symptoms do not vanish after interventions, and conform a 'demoralisation syndrome'. No published research on demoralisation's measure in the

Spanish context has been found.

**Aims:**

1) to introduce ant test Kissane's Demoralisation Scale in the Spanish palliative care context; 2) to report any differential outcomes for socio-demographic or diagnosis characteristics; 3) to report and discuss results from DS with those from relevant criteria as patients' spiritual well-being, dignity, among others.

**Design, methods and approach taken:** 128 patients admitted to treatment through Home Care Units, Continued Care Units and Long Term Hospital in the *General Hospital of Valencia*. Instruments were DS, HADS, GES-Q (spirituality), and CED-PAL (assessing dignity at the end of life). Descriptive and reliability statistics, correlations and MANOVAs to test for differences were obtained.

**Results:** Alphas for Kissane's dimensions of demoralisation ranged from .65 for Disheartenment to .89 for Loss of Meaning. MANOVAs revealed no differences by sex or diagnosis ( $F(122,5) = 0.25$ ,  $p = .94$ ,  $\eta^2 = .01$ , and  $F(244,10) = 1.15$ ,  $p = .32$ ,  $\eta^2 = .05$ , respectively). Anxiety, depression and threatened dignity were positive and significantly correlated with DS while spirituality and preserved dignity were negatively.

**Conclusions:** Demoralisation theoretically and empirically appears as key concept in quality of life in the Spanish palliative context. Further research on its dimensionality is needed.

**Abstract number:** P1-065

**Abstract type:** Poster

## Characterisation of a Palliative Care Population in a Comprehensive Cancer Centre

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**Background:** In cancer the Palliative Care Population (PCP) concept is subject to continuous change and there is a lack of consensus and clarity in the previously applied definitions.

**Aims:** The aims of this study were to identify the PCP in a comprehensive cancer centre and to analyse associations between Specialist Palliative Care (SPC) and sociodemographics, cancer diseases and treatment characteristics.

**Methods:** Patients were assessed to be included in a randomised clinical trial of accelerated transition from oncological treatment to SPC at home. The assessment period was from June to December 2013 and took place in a department of oncology. The screening was performed with a sequential alternation screening process. The PCP was defined as patients with incurable cancer and limited or no antineoplastic treatment options. Limited treatment options were defined for each cancer disease, e.g. breast cancer refractory to 3<sup>rd</sup> line treatment, lung cancer refractory to 1<sup>st</sup> line treatment etc. The data was analysed with descriptive statistics and multivariate logistic regression.

**Results:** During the study period 3717 patients with cancer were assessed. The PCP comprised 513 patients with incurable disease and limited treatment options yielding a prevalence of 13.8 %. Two-hundred and fifty-six patients with Performance Status 2-4 were defined as The Essential PCP (EPCP). They were older, more likely inpatients, had more comorbidity burden and 37.9% received Specialist Palliative Care (SPC). Women, patients without caregivers and breast cancer patients were more likely to receive SPC.

**Discussion:** Using clear criteria from clinical data seems a feasible method to identify the PCP. Due to the systematic screening the observed prevalence of 13.8% is generalisable to departments of oncology with similar composition of clinics for specific cancer diagnoses. Funded by Trygfondene and the Danish Cancer Society

**Abstract number:** P1-066  
**Abstract type:** Poster

## A Pilot Study to Assess the Appropriateness of the Palliative Care Outcome Scale (POS) within the Acute Stroke Population

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**Background:** Cerebrovascular disease (stroke) accounts for about 10% of total deaths worldwide and is associated with high mortality in the acute phase (1<sup>st</sup> 30 days post onset). There is evidence of deficiencies in palliative care for stroke but little information on how to measure palliative care needs and staff may be reluctant to broach end of life issues without appropriate tools.

**Aim:** To explore whether the POS can be used within the acute stroke population.

**Methods:** Consecutive adult acute stroke patients scoring < 15/20 on the Barthel Index (indicative of higher palliative care needs) admitted over a 26 week period into 3 acute stroke units in the UK were recruited. The POS was administered a week after admission and at day 28 (if still alive or in the unit) and analysed in terms of the range and mean scores.

**Results:** 514 patients were admitted to the units, of which 83 had a Barthel of < 15 and 23 participants consented to the study and had data collected. POS were self completed by 15 or completed by a carer (3) or staff (5) at day 7-14. Only 3 were completed at day 28 due to death (3) or participants having been being discharged (18). Scores ranged from 0-4 on all but 1 of the items; the highest average score was for family anxiety (2) and the lowest for time wasted on appointments (0.1). Staff expressed reluctance to use the POS due to a perceived lack of knowledge about the patients and reference to *palliative*.

**Conclusion:** Findings support the need for a palliative care assessment and patients reported valuing the opportunity to talk about issues that had not been addressed. However, the clinical setting and the acute onset of the condition highlighted problems with the appropriateness of some items of the POS and how to collect data from impaired patients. Data collection can be difficult due to the duration of stay on the acute stroke units as patients may be rapidly discharged to rehabilitation. A more stroke-sensitive POS may be appropriate.

Funding: LUECG



**Abstract number:** P1-067  
**Abstract type:** Poster

## Assessing Physical Performance in Non-small Cell Lung Cancer: Is the Short Physical Performance Battery Acceptable, Feasible and Able to Predict Fitness for Treatment?

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**Background:** Physical performance is the observable ability to perform physical functions. Many non-small cell lung cancer (NSCLC) patients present with impaired functional status. The performance status (PS) score in current use is subjective, and low inter-clinician agreement may result in inconsistent treatment planning. Objective performance tests, such as accelerometry, require days of compliance with monitoring and are not in routine clinical use. The Short Physical Performance Battery (SPPB) is a valid, reliable and responsive clinical test of physical performance in older people. It assesses lower limb strength and endurance, and has been used in NSCLC patients in research settings. However, its value in the routine oncology clinic setting has not been tested.

**Aims:** We aim to assess

- (i) acceptability and feasibility of the SPPB in patients attending a rapid access lung cancer clinic (RALCC) and
- (ii) whether it can predict fitness for treatment.

**Methods:** This is part of a prospective study of PS 0-2 NSCLC patients (target n=80, recruitment and analysis on schedule for completion in April 2015). SPPB and PS scores are collected at presentation to the RALCC; thereafter receipt of treatment is recorded longitudinally. SPPB comprises three timed components: balance (side-by-side, semi-tandem and tandem stands), 4-metre gait speed, and 5 chair rises.

**Results:** Acceptability and feasibility of SPPB will be presented descriptively, as well as discussion of its practicality in a busy clinic. Correlations between total and component SPPB scores, PS and receipt of treatment will also be reported.

**Conclusion:** Increasing evidence suggests that supportive interventions such as exercise may be beneficial, even for patients with advanced NSCLC. Measuring physical performance at baseline, in addition to the PS score, may therefore offer more value in defining individualised supportive care plans, and may allow more accurate prediction of fitness for treatment.

**Abstract number:** P1-068  
**Abstract type:** Poster

## Prognostic Value of PPS in Patients Attended at Home: Is it Also Useful?

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**Introduction:** Performance status is traditionally associated with survival in cancer patients. Most of the studies consulted are in inpatients.

**Aim:** We wonder if this variable, measured by the Palliative Performance Scale (PPS), is also a good prognostic tool in a home cohort.

**Methods:** A longitudinal, retrospective, survival study, along 2013. Inclusion criteria: >18 years old with advanced cancer, attended at home, with PPS value registered. Variables: age, gender, primary location, PPS, survival from first visit, delirium and place of death. Descriptive analysis and Kaplan-Meier survival functions were performed, as well as cox-regression. Authorisation for reviewing records was requested to the Ethical Committee.

**Results:** 473 patients were visited during 2013, 383 met inclusion criteria. The profile of our sample was a man of 74 years old with digestive and lung as most frequent locations. Most of them died at home (53%), and a few with delirium at first visit (12%). Median PPS was 50% (interquartile range 25-75: 40-60%), with median survival of 30 days (IQR 25-75: 12-67 days). PPS showed a great association with survival, with statistically significant differences

**Means and Media...** (Log Rank 258.7, p< 0.000), as well as delirium at first visit (p< 0.000). Patients with a better performance status in our first visit died more frequently in the hospital than at home (pearson chi-square 19.65; p< 0.000). Younger than 60 years presented a better performance status than older (pearson chi-square 6.37; p< 0.012). No association was found between primary location and PPS or survival. Cox-regression was positive for PPS value and delirium, with a mortality risk of 3.1 for each 10% in PPS.

**Conclusions:** PPS is also a good help for survival estimation for home care support teams.

PPS	MEAN	C195% UPPER BOUND	C195% LOWER BOUND	MEDIAN	C195% UPPER BOUND	C195% LOWER BOUND
< OR =20%	3.583	1.862	5.305	2	-	-
30%	24.436	13.239	35.633	14	8.756	19.244
40%	34.409	25.799	43.020	23	17.692	28.308
>40%	67.272	58.119	76.424	43	35.460	50.540
ALL	53.256	46.579	59.933	30	24.648	35.352

[Means and Medians of Survival according to PPS]

**Abstract number:** P1-069  
**Abstract type:** Poster

## Development of a Preference-based Outcome Measure for Use in Economic Evaluations of Palliative Care Services

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**Background:** The W.H.O passed the first ever palliative care (PC) resolution urging member states to implement policies supporting the integration of cost-effective PC services. Economic evaluations (EEs) are crucial in identifying the comparative clinical and cost-

effectiveness of competing PC interventions. However, there is a dearth of EEs of PC interventions which deprives decision makers of the basic information required to meet the needs of dying patients. The Quality Adjusted Life Year (QALY) is the preferred outcome in cost-utility analysis. In some medical fields (including PC), generic preference-based measures of health (PBMH) like the EQ-5D - which are commonly used to derive QALYs - have been found to be inappropriate.

**Aim:** To assess the feasibility of deriving a PBMH from the Palliative Outcome Care Scale (POS), for use in economic evaluations of PC interventions.

**Methods:** The POS was used to derive a health state classification using a 5-stage approach. Stage 1 uses factor analysis to establish instrument dimensions, Stage 2 excludes items that do not meet the initial validation process and Stage 3 uses criteria based on Rasch analysis and other psychometric testing to select the final items for the health-state classification. In Stage 4, item levels are examined and Rasch analysis is used to reduce the number of item levels. Stage 5 repeats Stages 1-4 on alternative data sets to validate the health-state classification.

**Results:** A unidimensional health state description consisting of 7 items was derived from Rasch analysis. A sub-sample of 14 plausible health states which can be used to obtain preference values were identified from the Rasch item threshold map.

**Conclusion:** Rasch analysis provides a useful means of developing plausible health states for valuation. This research will provide a basis for estimating QALYs to inform cost-utility analysis of palliative care interventions.

**Funders:** Atlantic Philanthropies; Cicely Saunders International

**Abstract number:** P1-070  
**Abstract type:** Poster

## Building a Taxonomy of Integrated Palliative Care Initiatives

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**Aims:** As part of an EU-funded project InSup-C a taxonomy of integrated palliative care (IPC) interventions has been developed. In order to investigate the provision of IPC all relevant categories and aspects within the process of care were identified. The taxonomy aims to establish a scheme against which existing interventions can be classified and supports the design of future integrated interventions. At best, the taxonomy represents a common yardstick for analysis and mutual learning.

**Methods:** A preliminary version of the taxonomy was constructed based on a systematic literature review, expert interviews and an online survey. The taxonomy was revised and consented in an expert workshop. The scope of the classification system to be invented was restricted both regionally (Europe) and in terms of its application (focussing on cancer, COPD and CHF).

**Results:** The final taxonomy encompasses the process of IPC as well as structure and working modes. Hence, the classification system developed by InSup-C consists of eight categories including two to four items each. For instance, the category *type of intervention* is divided into the items *pathway*, *model* and *guideline*. Likewise, the category *collaboration and communication*, aiming to classify the interaction between care givers involved in the provision IPC, is differentiated into the items *network*, *protocol*, *team* and *case management*. As a measurement tool, the taxonomy allows to evaluate IPC as well as to compare respective initiatives.

**Conclusion:** Developing a classification system has been a crucial task of the InSup-C project. The taxonomy will be applied to identify those initiatives of IPC that will be examined empirically in the continuation of the study. Thereby, it has to be tested whether the taxonomy is flexible and robust enough to cover IPC schemes in different health care contexts.

**Abstract number:** P1-071  
**Abstract type:** Poster

## What Is Stable Pain Control - Can a Personalized Pain Goal Help?

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**Background:** The Edmonton Classification System for Cancer Pain (ECS-CP) has been extensively validated and consists of five pain features: mechanism of pain, incident pain, psychological distress, addictive behavior and cognitive function. As an alternative to the definition for stable pain control used in the ECS-CP validation studies (i.e. pain intensity score of 3 or less and less than 3 breakthrough doses for 3 consecutive days), or other recommended definitions (i.e. 2 point drop in a 10 point scale or 30% decrease in pain intensity), the use of a personalised pain goal (PPG) has been suggested as having better prognostic importance as an outcome measure.

**Aims:** We hypothesised patient's PPG would differ significantly from the pain intensity score used in the ECS-CP study definition.

**Methods:** 300 advanced cancer patients were recruited from 2 acute care hospitals and a Tertiary Palliative Care Unit. A palliative care specialist completed an ECS-CP for each enrolled patient. Routine patient demographics included the patient's response to his/her desired pain intensity goal for pain control.

**Results:** 231/300 patients (77%) had a pain syndrome. 169/231 were able to give a PPG on initial assessment (3 declined to answer and 59 were too cognitively impaired): the median PPG was 3 (range: 0-10). Almost half (74/169, 44%) had a PPG that was the same as the study definition (i.e. 3). Most (154/169, 91%) had a PPG between 2-5. The remaining patients either had a PPG between 1-1 (6/169, 3.6%) or 6-10 (9/169, 5.3%). 103/169 achieved stable pain control (61%).

**Conclusion:** The majority of PPG scores did not differ significantly from the study definition, suggesting that for research purposes this definition is a close representation of pain intensity goals for stable pain control. However, for individual patient management, it would be important to include the PPG as part of standard clinical practice, given the wide range of responses.



Abstract number: P1-072

Abstract type: Poster

## Using Confusion Assessment Method for Detection Delirium among Hospice Patients - Screening or a Diagnostic Instrument?

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**Background:** Delirium is a common condition, affecting up to 80 % of terminally ill patients. Identification of delirium can be difficult, because the symptoms can be mistaken for other conditions like depression, dementia and so on. Our hypothesis is that patients with hyperactive delirium (heightened arousal, restlessness and agitation) are easier recognised than the hypoactive delirium (Patients withdrawn, quiet and sleepy). A Danish national Guideline (2013) recommends systematic screening by the Confusion Assessment Method (CAM), which is validated as having high sensitivity and specificity.

**Aims:** The aim of this study was to evaluate the use of CAM, as a diagnostic tool, in our Hospice.

**Methods:** A retrospective study

From 1.4.2014, all patients admitted to our hospice were screened with CAM every evening as well as if the patient was suspected of having delirium.

The patient notes of 61 patients admitted to Hospice from 1.4. until 20.7.2014 were examined. The results of the CAM score were registered and compared with documentations on psycho-social conditions.

**Results:** Out of 61 patients, 2 were excluded because the CAM score wasn't done. 59 patients were included. 19 patients were in delirium according to the CAM score (32%). Documentations on psycho-social conditions detected that 25 patients were diagnosed and treated for delirium (42%). 4 of the 6 patients, who weren't identified by CAM, were in terminal delirium (< 3 days to death) and 2 patients were assessed to have a hypoactive delirium. With a total of 4 hypoactive delirium patients in the study, only 50 % were discovered by the CAM.

**Conclusion:** Our once a day screening by CAM, during the evening, did not find all patients with delirium. Screening when delirium was clinically suspected was more effective at identifying delirium.

In the future it's still important to focus on the hypoactive condition, which is difficult to identify because the symptoms can be confused with e.g. fatigue of the terminally ill.

Abstract number: P1-073

Abstract type: Poster

## Validation of the Observational and Behavioural Scale (EOC) for Adult Patients

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Most of behavioural pain assessment tools focus on elderly, paediatric or sedated patients. With four items, the François Boureau Behavioural Scale (ECFB) focuses on patients over 15 years old. In agreement with the author, a fifth item evaluating aggressiveness or mutism was added and this modified scale was called the Observational and Behavioural Scale (EOC). EOC matches the six behaviours required by the American Geriatrics Society. Our aim was to statistically validate EOC's feasibility, validity and reliability.

This is a comparative and transversal study. Thirty units participated between November 2007 and March 2008. EOC was evaluated during the same time by a non-trained caregiver and a pain expert, blinded of each other results. Next, a reference test was performed: Numerical Scale (NS) for Communicating Patients (CP) or ECPA2 for the Non-Communicating Patients (NCP).

395 CP and 52 NCP were included and analysed, 86 excluded.

All EOC were performed in less than 1 minute, all items were understandable and the filling rate of each item was between 99,6% and 99,9%.

EOC's correlation with standard tests was good (Spearman's coefficient: with NS  $p=0,49$ ; with ECPA2  $p=0,82$ ). ROC analysis showed the best positivity threshold was 1/10 for CP (Se=71%;Sp=73%) and 3/10 for NCP (Se=87%;Sp=97%).

Only the first four items for CP and all items for NCP were correlated with one another and informative (Principal Components Analysis: Factor loading>0,40 and Cronbach's  $\alpha>0,70$ ). The reproducibility of EOC was good (Intraclass Correlation Coefficient: CP group 77%, NCP group 93%).

EOC can be filled shortly and its understanding is simple thanks to the short explanations provided within it. It's the only scale validated in French especially focused on adult patients. EOC is correlated with standard tests and its reproducibility is good. EOC is highly relevant with NCP, its specificity excellent.

It was generalised in our institution to complete self assessment or replace it.

Abstract number: P1-074

Abstract type: Poster

## Development of a New Tool for the Assessment of the Psychosocial Needs of End-of-Life Patients

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**Background:** Providing palliative care to end-of-life patients (EoLP) requires knowing which aspects of psychosocial nature can contribute to the patients' well-being. For this, we must have reliable, simple and specific assessment tools.

**Aims:** To develop an instrument (Psychosocial Needs Evaluation; PNE) to assess and monitor the psychosocial needs of EoLP taken care by PC teams.

**Methods:**

1) bibliographical review;

2) build-up of the experts panel;

3) discussion and agreement on the most relevant dimensions in psychosocial care;

4) description of key indicators and consensus on the questions for each dimension,

5) exhaustive revision of the tool by external professional experts (including physicians, nurses, psychologists and social workers) in palliative care and

6) revision of the tool by expert patients.

**Results:** The PNE includes 18 questions distributed in 5 dimensions: emotional, coping, communication / relationships, spirituality and well-being. 30 professional experts in PC included comments on the questions, the way they were formulated, the answer options, the dimensions evaluated at each question and improvement proposals. They also revised the instructions for the tool's administration. They all qualified the tool as being excellent. To improve it, they suggested to reduce the number of questions and to change the answer format (from a numerical scale of 0-10 to a Likert scale).

Additionally, 20 expert patients revised the tool. They considered the questions to be very clearly or clearly understandable and suggested some changes. They also appreciated their participation in the study and considered very important being asked about these issues.

**Conclusions/ discussion:** The PNE tool allows assessing EoLP patients' needs systematically and holistically. We believe that the scale improves the understanding of the psychosocial needs of EoLP, and provides a more comprehensive palliative care approach, specific, individualised and effective.

Abstract number: P1-075

Abstract type: Poster

## Case Finding for Advanced Chronic Patients in Need of Palliative Care Approach at High Risk of Death in the Next 12 Months: Development of a Predictive Model

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**Background:** 75% of deaths in high-income countries are caused by progressive advanced chronic conditions. Identifying advanced chronic patients in need of palliative care (PC) approach at high risk of death can be crucial to provide intervention.

**Aims:** To determine factors associated with mortality and to develop a predictive model to identify advanced chronic patients in need of PC approach at high risk of death in the next 12 months.

**Methods:** 995 patients with advanced chronic conditions in need of PC approach as assessed by healthcare professionals using the NECPAL CCOMS-ICO<sup>®</sup> tool (NECPAL+) were included in an observational, analytic, prospective cohort study. Cox regression analysis was used to identify which NECPAL CCOMS-ICO<sup>®</sup> tool indicators were associated with mortality within 12 months after NECPAL+ identification. A predictive model was created based on selected factors. Sensitivity, specificity and the area under the Receiver Operating Characteristics (ROC) curve were calculated.

**Results:** Mortality rate at 12 months was 25.9%. Factors associated with 12-month mortality were: consideration by healthcare professionals that patient requires PC (Hazard ratio (HR)=2.62), surprise question (HR=2.00), request from patient for PC or limitations of major therapeutic interventions (HR=1.67), functional dependency (HR=1.42), functional decline (HR=1.39), request from main carer for PC or limitations of major therapeutic interventions (HR=1.38), nutritional decline (HR=1.38),  $\geq 2$  admissions in previous year (HR=1.18) and Charlson score  $\geq 2$  (HR=1.11). Area under the ROC curve=0.77. At a cut-off point of 0.08, 70.2% (sensitivity) of patients who died and 70.4% (specificity) who did not died were successfully predicted.

**Conclusion:** We present an acceptable predictive model that can be used to assess the mortality risk of individual patients in the next 12 months.

**Source of funding/ Reference:** P110/01512. Institute of Health Carlos III. Ministry of Health. Government of Spain.

Abstract number: P1-076

Abstract type: Poster

## A Cross-sectional Study of Self-reported Difficulty in Climbing Up and Down Stairs as a Predictor of Falls and Functional Status in Elderly Patients with Prostate Cancer

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**Background:** Falls in the elderly cancer patient cause a significant amount of morbidity and mortality. There is no simple tool for the oncologist to use in the clinical setting to identify cancer patients with a high risk for falls. This study's objective was to determine if a questionnaire of self-reported difficulty in climbing up and down stairs correlates with functional tests and self-reported history of falls.

**Patients and methods:** Older males (N=34; mean age 72.6 y) with prostate cancer were assessed during a single oncology visit. They completed questionnaires evaluating difficulty climbing up and down stairs, history of falls and independence in activities of daily living, and three objective tests of function (the Timed Get Up and Go Test [TGUG], Unipedal Stance Test, and Grip Strength Analysis).

**Results:** Of 33 patients completed the assessments, 15 reported difficulty in climbing up and 10 in climbing down stairs (9 both). Difficulty in climbing up stairs was associated with a significantly longer TGUG test time and less grip strength. Difficulty climbing down stairs was associated with a significantly longer TGUG test time and less independence in activities of daily living. Both climbing up and down stairs were associated with number of falls in one year (sensitivity was 81% and specificity was 83%).

**Conclusions:** Self-reported difficulty in climbing up and down stairs closely correlates with objective functional testing and number of reported falls in one year. This questionnaire may be a useful clinical tool for screening high fall risk cancer patients.

# Poster Sessions (Poster Exhibition Set 1)

**Abstract number:** P1-077

**Abstract type:** Poster

## Status of Prognosis Prediction in Terminal Cancer Patients at a Japanese General Hospital

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**Background:** Evaluating prognosis prediction in terminal cancer patients is very important in providing appropriate palliative care at the right time. At our hospital, we have used the Palliative Prognostic Score (PaP Score) to estimate prognosis since August 2011. Here, we describe the status of prognosis prediction in terminal cancer patients at a Japanese general hospital.

**Method:** We retrospectively analysed 149 patients in whom prognosis was predicted using the PaP Score at the time of admission between August 2011 and July 2014, after cancer treatment discontinuation.

Patients were divided into groups according to their PaP Score: group A (0-5.5), group B (5.6-11.0), and group C (11.1-17.5). We compared the results of our survival analysis in these groups with the results of a previous study.

Next, we compared actual survival time with Clinical Prediction of Survival (CPS), a structural component of the PaP Score. Survival was analysed using the Kaplan-Meier method and compared between groups using the log-rank test.

**Result:** Median patient age was 72 years, and 58% of patients were men. The primary cancer site was the pancreas and bile duct in 20.1% of patients, the gastrointestinal tract in 51.0%, and the respiratory tract in 14.1%. The total PaP Scores were 6.7%, 40.9%, and 52.3% in groups A, B, and C, respectively.

The actual median survival times were 26 (95% confidential interval [CI]: 23-29), 18 (95%CI: 15-21), and 10 (95%CI: 7-13) days in groups A, B, and C

CPS was consistent with actual survival in 36.0% of cases; longer, in 41.3% of cases; and shorter, in 22.7% of cases.

**Conclusion:** Actual survival in our study was shorter than that in the previous study, especially in patients assigned to group C according to the PaP Score. However, the results should be interpreted carefully, considering the differing patient backgrounds between the two studies. Predicted survival tended to be longer than actual survival.

**Abstract number:** P1-078

**Abstract type:** Poster

## The Patient's View: 268 Advanced Cancer Patients' Self-reported Prioritized Symptoms and which HCP Took Care of them

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**Background:** Advanced (adv) cancer patients (pts) face a variety of SY which are variably managed by different health care professionals (hcp).

**Aims:** To investigate the frequency of pt-prioritised SY, the intensity of pt-reported SY and the pt-perceived involvement of hcp in their management (mgmt).

**Methods:** The reported data is part of a larger study (268 adv cancer pts, defined palliative care (PC) needs, 74% ECOG 1+2), monthly collection of pt perceived needs/recalled delivery by hcp for 7 PC key interventions, demographics (adapted EAPC dataset), PC needs (IPOS), QoL (EQ5D), and quality indicators (QI, inappropriate anticancer treatment, aggressive end-of-life care, quality of dying). For the current analysis pts were asked to prioritise their distressing SY in the past 6 months and whether these were addressed by hcp.

**Results:** Prioritised SY were pain (185, 69% of pts, IPOS mean score 1.9), fatigue (149, 56%, 2.1), anorexia (103, 38%, 1.2) nausea (82, 31%, 1.0), breathlessness (54, 20%, 1.0), anxiety (36, 13%, N/A), and depression (28, 10%, N/A).

No SY was addressed in 16%, partially in 43%, and all in 41% of pts. Doctors addressed 75%, doctors/nurses 21%, nurses 5% of the SY. Nausea was addressed in 82%, pain in 81%, breathlessness in 78%, anxiety in 58%, depression in 50%, anorexia in 40%, fatigue in 39%. Nurses alone addressed most frequently anxiety (10%), nurses/doctors fatigue (29%).

Analysis on correlations of prioritised SY/IPOS scores, association of pt characteristics (tumour types, demographics) on SY and the influence of SY mgmt incl. drugs/ individual longitudinal pt data on QI is ongoing.

**Discussion:** SY epidemiology in Romanian adv cancer pts seems comparable to other populations including silent SY. The substantial lack of pt-perceived adequate SY mgmt, the doctors central role, and nurses involvement in psychological (anxiety) and fatigue mgmt suggest the need for increased multiprofessional education and care processes.

**Funding:** SNF Grant IZERZO\_142226

**Abstract number:** P1-079

**Abstract type:** Poster

## Comparison of Symptom Control Effectiveness Provided by Two Health Care Teams to Patients with Advanced Cancer

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**Introduction:** The effectiveness of different strategies of palliative care provision is little known.

**Objective:** To compare symptom control effectiveness provided by two health care teams: interconsultation palliative care (IPTC) and non-palliative care (NP).

**Method:** Pragmatic clinical trial carried on 138 consecutive adults with advanced cancer, admitted in oncology hospital (2012-2013), who presented pain intensity  $\geq 4$  (0-10) or at least others two symptoms with intensity  $\geq 4$  (0-10). 53 patients were attended by IPTC and 87 by NP. All were interviewed at admission, after 24h and 48h from admission. Symptoms were measured by the Edmonton Symptom Assessment System (ESAS). The sum of ten

symptom scores (ESAS with sleep) was defined as the symptom burden. The endpoints were 2 points reduction of the initial pain or other symptoms scores after 48h from admission and 20 points reduction of the initial symptom burden score after 48h from admission. Multiple Poisson regression analysis adjusted for age, KPS and number of metastasis was used to analyze the occurrence of the endpoints. The significance level adopted was 5%.

**Results:** The symptoms burden average score at admission were 44 (SD=2.3) in IPTC group and 45 (SD=1.5) in NP group. After 48h from admission, symptom burden improved only in NP group ( $p < 0.001$ , Wilcoxon test). Poisson's regression showed relative risk reduction of 2 points in constipation score (RR=3.2[95%CI 1.16-8.93]) favorable for IPTC group; and in pain score (RR=0.6[95%CI 0.38-0.98]) for NP group.

**Conclusion:** Patients showed moderate symptoms burden at admission in IPTC and NP groups; and after 48h from admission the symptoms control were poor in both groups. Only constipation in IPTC group and pain in NP group showed minimum clinically important difference.

**Abstract number:** P1-080

**Abstract type:** Poster

## Interprofessional Team Use as a Measure of Complexity of Pain Management Needs

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**Background:** The Edmonton Classification System for Cancer Pain (ECS-CP) has been extensively validated and consists of five pain features: mechanism of pain, incident pain, psychological distress, addictive behavior and cognitive function. Outcome measures for complexity of pain management have included time to stable pain control, opioid dose and adjuvant analgesic use. Patients with psychosocial distress complicating pain management may require more interprofessional (IP) team resources as a measure of pain management complexity. This has not been previously studied.

**Aims:** We hypothesised patients with less problematic features as classified by the ECS-CP would require a shorter time to achieve stable pain control, use less complicated analgesic regimens and require less IP team resources.

**Methods:** 300 advanced cancer patients were recruited from 2 acute care hospitals and a Tertiary Palliative Care Unit (TPCU). However, only the 100 patients recruited on the TPCU had access to a complete IP team and were included in this component of the study. IP team members (psychology, spiritual care, social work, music therapy and rehabilitation) recorded time spent with patients on a daily record.

**Results:** 98/100 had a pain syndrome. 66 achieved stable pain control and used an average of 4.5 hours (SD 3.7). 20 died before stable pain control and used an average of 4.5 hours (SD 3.8). 12 were discharged before stable pain control and used an average of 9.5 hours (SD 8.2) of IP time, which was significantly higher than the other two groups ( $p = .002$ ). Significantly more IP time was used for patients with neuropathic pain and psychological distress ( $p < 0.05$ ).

**Conclusion:** The intricacy in collecting this data and confounding variables driving IP team use make this a challenging variable to include as an outcome measure of complexity of pain management needs. Future studies need to consider other approaches for assessing the impact of IP team involvement.

**Abstract number:** P1-081

**Abstract type:** Poster

## Use of the VOICES-SF among Bereaved Carers in Denmark: Validation and Cultural Adaptation

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**Background:** Our main study aimed at assessing quality of care in the last three months of the patient's life, as well as circumstances surrounding death, by questionnaires answered by the bereaved relatives. In interviews with Danish patients, relatives and professionals important themes were identified. These themes were to a large extent covered by the British questionnaire 'Views Of Informal Carers - Evaluation of Services - Short Form' (VOICES-SF), and this instrument was therefore selected. A few adaptations (including addition of items assessing home care by a specialist palliative team) were made.

**Aims:** To validate the VOICES-SF in a Danish setting and test the feasibility of using this questionnaire among bereaved carers.

**Methods:** The slightly modified Danish version of VOICES-SF was tested in cognitive interviews with 36 bereaved relatives of deceased cancer patients. Verbal probes (i.e. questions about the items) were prepared and supplemented with 'think aloud-responses' in telephone interviews covering a large geographic area.

**Results:** The mean duration of the interviews was 60 minutes (range 25 - 120). The VOICES-SF was found feasible and easy to answer. It was not regarded as unnecessarily upsetting and items were generally comprehended as intended. However, one item regarding the general practitioner was frequently misunderstood and was therefore changed in the final Danish version of the questionnaire. A few items would benefit from adding a 'not relevant' response category but this was not done, because comparability with the British version was seen as more important.

**Conclusion:** The VOICES-SF worked well in Denmark after a slight cultural adaptation. Bereaved carers were positive towards the use of this questionnaire. One item was frequently misunderstood in the Danish sample, and its validity should also be tested in other countries.

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**Abstract number:** P1-082  
**Abstract type:** Poster

## The Use of a Brief 5-item Measure of Family Satisfaction as a Critical Quality Indicator in Advanced Cancer Care

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**Background:** Family satisfaction is a critical indicator of quality of care for patients with advanced illness that is commonly measured in palliative care research. Yet the systematic assessment of family satisfaction as a quality indicator is rarely practiced despite an emphasis on the importance of family input and support for caregivers in advanced care for those with cancer and other serious illnesses. Measurement burden may be one barrier to widespread use of family satisfaction measures.

**Methods:** We used data from the Palliative Care for Cancer Patients study, a multisite observational study of the effect of inpatient palliative care on patient health outcomes and health services use among patients with advanced cancer. Using Item Response Theory we developed a shortened 5-item version on the FAMCARE scale to measure family satisfaction with care. We used multivariate regression analysis to detect significant differences across five treatment sites controlling for patient demographics, cancer type, family relationship to patient and use of inpatient palliative care.

**Results:** Family satisfaction data were available on 1979 patients. The most common cancer type was GI (28%) followed by lung (13%). Mean FAMCARE-5 score across sites ranged from 5.54-6.89 out of 10 indicating highest level of satisfaction. Family members of patients at site 5 (n=783) were significantly ( $p < .01$ ) less satisfied with their care than family members at other care sites.

**Discussion:** Variability in family satisfaction with advanced cancer care across sites can be detected using a brief 5-item questionnaire. The development of less lengthy and burdensome measures for monitoring family satisfaction among patients with serious illness can facilitate the routine assessment of family satisfaction to maintain and promote high quality care across care settings.

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**Abstract type:** Poster

## Development of a Questionnaire to Evaluate Quality of Palliative Care

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**Background:** In Sweden, palliative care is provided across a variety of care settings by a range of professions, supported by recently developed national guidelines. The quality of palliative care is evaluated with a national register focusing the last week of life. However, there is need for defining feasible measures of quality of palliative care.

**Aim:** To develop a questionnaire evaluating quality of palliative care from the perspective of health care professionals at different care settings.

**Methods:** The core issues in national clinical practice guidelines for palliative care were chosen to represent quality of palliative care. To generate items, a brief inventory on existing questionnaires was undertaken and items from three existing questionnaires were rewritten to represent staff perspectives. To check for relevance, coverage and face validity an expert group reviewed the items. A first version asking for comments was answered by 10 nurses in specialised palliative care, 4 nurse assistants in elderly care, one nurse and one social worker from paediatric oncology. The questionnaire was somewhat revised and completed by 99 professionals to explore response patterns. For further refinements, the questionnaire was critical reviewed by an expert on questionnaire construction. Finally, cognitive interviews with health care professionals were conducted.

**Results:** All items were considered relevant but some were unclear and revised to improve readability. Some relevant issues were experienced not covered, consequently new items were added. During the validation process, the response alternatives were refined. At this point the questionnaire consists of 40 items covering the core dimensions; symptom management, dialogue and support, involvement, encounter and organisation of care.

**Conclusion:** The questionnaire seems to have content validity. After evaluating measurement properties, this questionnaire can be used nationally to evaluate the quality of palliative care.

**Abstract number:** P1-084  
**Abstract type:** Poster

## Constructing Connection through a Shared Assessment Process

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**Background:** A global increase in demand for palliative care is driving capacity building for all nurses. The purpose of using validated assessment scales in nursing is to pursue holistic care. A number of scales are utilised by palliative care teams however these tools have not been extensively used by generalist nurses.

**Aim:** This study reports the findings of implementing a shared palliative care clinical assessment process on a general medical ward at a regional hospital.

**Methods:** Three-phased mixed method study. The awareness level of five validated assessment scales and the frequency nurses experienced difficulty in communicating patients change in status was recorded at the pre, mid-term post study points in a short questionnaire. The assessment process was completed on a daily basis, audited mid and post study. Analysis was conducted using the SPSS version 21. Focus groups were held at the end of data collection and descriptive analysis was employed to identify emerging themes from semi structured open ended interview questions.

**Results:** Thirty one nurses participated. No nurses were extremely aware of the five validated scales with 54.28% having no awareness at all pre study. Post study, 28.88% of the nurses were extremely aware with 37.77% of nurses being very aware of the scales. Prior to the

study commencing 59.08% of nurses experienced occasional difficulty in communicating patients change in status with 20.61% having difficulty post study. Eighty four to 97% of the scales in the daily assessment form were correctly recorded. Emerging themes included: the process was relatively easy to complete, it assisted in holistic assessment and improved communication.

**Conclusion:** A structured clinical assessment process can increase the span of assessment skills of general nurses. Extending the use of this assessment process in other general hospitals would further capacity building in the provision of palliative care. Nurses Memorial Foundation SA Inc.

**Abstract number:** P1-085  
**Abstract type:** Poster

## Life after Liverpool Care Pathway (LCP): Experiences of Critical Care Practitioners in Delivering End-of-Life Care since Discontinuation of LCP

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**Background:** Liverpool care pathway (LCP) widely used with an aim to improve communication and care for dying individuals and their relatives. However, widespread media criticism prompted a review resulted in the discontinuation of LCP across all UK clinical settings.

**Aim:** This study aimed to explore experiences, challenges and practices of critical care practitioners since the discontinuation of LCP in critical care settings.

**Methodology:** A qualitative exploratory design was used. After full ethics approval, semi structured interviews were conducted with fourteen critical care practitioners in two acute NHS trust hospitals in England.

**Results:** Analysis of the data revealed *life after LCP* as core construct with three key themes; firstly, the theme '*lessons learned*' explores the benefits and pitfalls of using LCP in the past. Secondly, the theme '*uncertainties and ambivalences*' illuminates the clinical challenges and issues around caring for end-of-life patients in critical care settings since the discontinuation of LCP. The final theme '*the future*' informs components of future care plan development relevant to end of life care in critical care settings.

**Conclusions:** We posit two key conclusions. Despite experienced critical care practitioners being able to deliver quality end of life care without utilising the LCP, inexperienced staff, both nursing and medical, need clear guidelines and the support of experienced mentors in practice. Similarly, evidence based guidelines related to family involvement in end of life care planning within the critical care setting is needed to avoid future controversies.

**Abstract number:** P1-086  
**Abstract type:** Poster

## Discovering the Hidden Benefits of Cognitive Interviewing in Two Languages: The First Phase of a Validation Study of the Integrated Palliative Care Outcome Scale (IPOS)

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**Background:** The Integrated Palliative care Outcome Scale (IPOS) is a newly developed advancement of the POS which assesses palliative care concerns as perceived by patients and healthcare professionals (HPs).

**Aims:** To assess patients' and HPs' views on IPOS in two languages with a focus on comprehensibility and acceptability, and subsequently refine the questionnaire.

**Methods:** Concurrent cognitive interviews were conducted in the UK and Germany with patients and HPs in different palliative care settings (palliative care inpatient, general hospital inpatient, community), to elicit problems with answering the questionnaire. Interviews were conducted using 'think aloud' and concurrent verbal probing techniques, audio recorded, transcribed verbatim and analysed by two researchers in each country by content analysis. Results from both countries were collated and discussed between both research teams and the IPOS was refined based on consensus decisions.

**Results:** In Germany and the UK, 15 and 10 interviews with patients (median age 65 yrs, range 22-85 yrs and 61 yrs, range 43-83 yrs, 10 and 7 female) and 8 and 10 interviews with professionals (3 and 5 nurses, 5 and 6 other professions) were conducted. Overall, the acceptability of the measure was high. The use and analysis of interviews in two languages resulted in wider consideration of meaning and context of each item. Issues arising comprised

1. comprehension problems with the wording of specific questions (e.g. 'mouth problems', 'felt good about yourself')
2. problems with questions and answer options that were regarded as too long and complicated.

All these issues were taken into account in the refinement of the IPOS.

**Conclusion:** Cognitive interviews conducted concurrently in two languages yielded common problems of the IPOS in both countries and ensured greater depth of consideration for each item. This led to a better overall refinement of the questionnaire. Phase 2 of validation using the refined IPOS measure is now underway.



## Audit and quality improvement

**Abstract number:** P1-087

**Abstract type:** Poster

### Translation of the Social Difficulties Inventory into German and Psychometric Analyses in Two Samples of Cancer Patients with and without Palliative Condition

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**Background:** Psychosocial support in palliative care of cancer patients should rely on patients' individual requirements, thus good screening instruments are needed. The Social Difficulties Inventory (SDI, Wright et al., 2011) aims to identify patients who require further support.

**Aims:** Translation of the SDI into German and psychometric evaluation in two samples of cancer patients with and without palliative condition.

**Methods:** Following recommended guidelines for translation of questionnaires:

1. translation and back translation,
2. patients' evaluation of cultural equivalence,
3. psychometric evaluation considering factor structure, internal consistency and construct validity.

For pretest two samples with a total of 27 patients were interviewed. Psychometric evaluation was examined in cancer patients who were recruited from an outpatient radiation clinic (n=229) and replicated in a sample of palliative patients (n=166).

Confirmatory factor analysis was used and subscale reliability was evaluated using Cronbach's  $\alpha$ . Construct validity was examined via correlations with distress and symptom burden.

**Results:** Forward - backward translation resulted in minor amendments and cultural adaptations. The German SDI was rated as acceptable and clear by the majority of interviewed patients. Factor analysis confirmed the 3-factor solution (money matters, everyday living, self and others) and could be replicated in the palliative sample. Floor effects were demonstrated in the money matters-subscale. Satisfactory internal consistency was demonstrated for all subscales ( $.62 < \alpha < .88$ ) and construct validity was confirmed.

**Conclusion:** The German translation of SDI is culturally and linguistically acceptable and can be used for cancer patients with and without palliative condition. Psychometric properties could be verified in both samples inspected. The money matters-subscale should be handled with caution because of the floor effects.

**Funding:** German Cancer Aid

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**Abstract type:** Poster

### Serum Magnesium for Prognostication of Survival in Advanced Cancer

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Serum magnesium levels (Mg) seem to be associated with nutrition status, cellular health, inflammation and proved to be an independent predictor of survival in various non cancer patient populations. Its prognostic usefulness in patients with advanced cancer has been barely elucidated.

**Objective:** To examine the relationship between the SML and the overall survival of advanced cancer patients.

**Methods:** Retrospective collection of demographic, clinical [type of neoplasm, ongoing treatment, Palliative Prognostic Scale (PPS), Palliative Prognostic Score (PaP)] and biochemical [Mg (mg/dl), albumin (alb g/l), C reactive protein (CRP mg/dl) and calcium (Ca mg/dl)] data at admission to a hospital-based palliative care team. Univariate and multivariate survival analysis were performed and the correlation of Mg with other prognostic variables was examined.

**Results:** From 178 new cancer referrals 105 (59%) were eligible for analysis (52% were female, median age 67 years, 39% with colorectal or breast cancer, 53% ongoing active treatment, median PPS 40%, median PaP 5, and a median survival of 75 days (95% confidence interval 56-94). The median Mg was 2.0 (range 0.9-3.2). The median survival for patients with Mg < 1.71, 1.71 to 2.10 and >2.11 was 124 days, 75 days and 31 days, respectively. However this was only a trend toward significance (p=0.06). No correlation was found between Mg and CPR, alb or PaP, independent predictors of survival in this population. The Ca/Mg ratio wasn't also a prognostic factor in our advanced cancer patients. **Conclusion:** The trend toward a decreased risk of mortality of patients with lower Mg levels should be prospectively studied in a large sample.

**Abstract number:** P1-089

**Abstract type:** Poster

### Development of the 'DESIGNER' Screening Tool to Detect Chronic Gastrointestinal Symptoms in Cancer Patients Following Pelvic Radiotherapy: A Cognitive Interview Study

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**Background:** Pelvic radiotherapy forms part of the optimal treatment of various malignancies. Although often effective, significant gastrointestinal problems occur in around half of patients who receive pelvic radiation. These symptoms are both under reported and under investigated in the UK and can have a profound impact on patients' lives. Current screening tools are lengthy and not routinely used in outpatient settings to identify patients at risk.

**Aims:** Develop and refine a simple screening tool to be completed by patients in outpatient clinics, to identify significant gastrointestinal side effects. This could improve symptom control and quality of life post treatment by increasing access rates to a specialist gastroenterologist.

**Methods:** Following an expert consensus meeting, a draft screening tool was tested for its usability and acceptability with patients experiencing gastrointestinal symptoms following pelvic radiotherapy; semi-structured, cognitive interviews were undertaken with 12 patients, recruited from oncology and gastroenterology outpatient clinics. Thematic analysis and probe category were used to analyse interview transcripts. Interview data were presented to a group of experts to agree on the final content and format of the tool.

**Results:** Overall, participants reported the screening tool to be acceptable in terms of wording, response format and completion time. Participants reported personal experiences which led to modifications to the tool. The tool has three questions covering numerous categories including rectal bleeding, incontinence, nocturnal bowel movements and impact on quality of life.

**Conclusion:** The DESIGNER screening tool will be used in clinical practice to improve post treatment supportive care by identifying patients suitable for referral to a gastroenterologist. DESIGNER will be further validated in an upcoming clinical study (EAGLE).

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**Abstract type:** Poster

### Patient Preferences for Cancer Symptom Assessment Scales

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**Background:** Systematic symptom assessment is essential in cancer. Symptom assessment instruments detect more symptoms than a clinical evaluation. Assessment burden and low completion rates are among the challenges that clinicians face in the selection of assessment scales for polysymptomatic cancer patients.

**Aims:**

1. To determine patient preference for symptom assessment scales in advanced cancer:

- a. Visual analogue scale (VAS)
- b. Numerical rating scale (NRS)
- c. Categorical rating scale (CRS)

2. To assess the clinical utility of each assessment scale.

**Methods:** A prospective survey is in progress to evaluate participants' preferences when describing symptom prevalence and severity. Pain, fatigue and loss of appetite are each measured by VAS, NRS and CRS. Participants' scale preferences are recorded for each symptom. Researchers' perceptions of ease of use for each scale are recorded to assess clinical utility. Study population: Consecutive inpatient cancer admissions are being recruited at a hospice. Method of statistical analysis: Descriptive statistics and correlations examine scale preference and the concordance of scores for each symptom and scale.

**Results:** 75 participants have been recruited to date with a median age of 69 years (range 38-93). Median Eastern Cooperative Oncology Group (ECOG) score was 1 (range 0-4). Results indicated a primary preference for NRS for pain (43%), with CRS for both fatigue (37%) and loss of appetite (47%). Researchers perceived NRS to be of highest clinical utility for both pain and fatigue, but CRS to be most appropriate for the assessment of appetite loss.

**Conclusion:**

1. 47% preference for the loss of appetite CRS.
2. The VAS was consistently the least preferred measure.
3. Participant preference for assessment scales varied across symptoms.
4. Researcher's perception of clinical utility correlated with patient preference on pain and loss of appetite scales.

**Abstract number:** P1-091

**Abstract type:** Poster

### Using Electronic Tablets to Collect Outcome Data in Palliative Care - Help or Hindrance?

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**Background:** Patient-reported outcome measures (PROMs) are perceived to be the gold standard when assessing patients' symptoms and concerns. Traditionally, such measures have been collected using paper questionnaires. Handheld devices, such as electronic (e)/tablets and smart phones, may be equally or better suited for the task. However, the acceptability and feasibility of such devices in palliative care settings is not known.

**Aims:** This study sought to assess whether the use of tablets for collection of PROMs was feasible and acceptable in hospital palliative care populations.

**Methods:** As part of a larger trial, in- and out-patients from two urban hospitals in the UK completed a set of outcome measures on paper or an e/tablet. A subset of patients was then invited to participate in a short telephone survey and interview to explore their experience of completing the PROM and to discuss their preferred format. Additionally, research nurses who supported patients during completion were interviewed after the study. Interviews were transcribed and analysed in Nvivo using thematic analysis.

**Results:** Ten patients and 2 research nurses took part in the study. Satisfaction was high and patients found both paper and e/tablet formats easy to read, use and navigate. Most were happy to recommend whichever format they had used, indicating that both formats are acceptable to patients. However, a few issues with e/tablet devices were identified from patient and nurse interviews. These included problems with reactivity of the touch screen, poor wifi signal in some areas, and an inability to see how much of the PROM had been completed.

**Conclusion:** Overall, palliative care patients found the e/tablet format equally acceptable to paper and e/tablet use in hospital palliative care settings appears feasible. However, some problems when completing PROMs on e/tablets were identified that should be addressed before such technologies are introduced more widely.



**Abstract number:** P1-092  
**Abstract type:** Poster

## Impact of a Palliative Care Consultation Team on Medication Changes before Palliative Care Unit Admission in a Japanese Comprehensive Cancer Center

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**Background:** Patients with advanced cancer suffer from various symptoms. Palliative care consultation team (PCT) have to immediately alleviate symptoms and also relieve suffering from unnecessary medications in such patients.

**Aims:** This study aimed to investigate changes in medication profiles among patients with advanced cancer before PCT referral (T1) and on admission to the palliative care unit (PCU) (T2).

**Methods:** We enrolled consecutive patients referred to the PCT and then transferred to a PCU from April 2013 to September 2014. Profiles of medications at T1 and T2 were recorded retrospectively. The Wilcoxon ranked-sum test and chi-square test were performed to analyse changes in opioid dosages and medication use, respectively.

**Results:** In total, 70 patients were analysed (female, 37%; median age, 61 years). Median period from admission to the oncology ward to T1, and from T1 to T2 were 5 days (interquartile range, 1-12) and 15 days (interquartile range, 7-24), respectively. Medications for symptom control including adjuvant analgesics, steroids, and neuroleptics were all significantly increased ( $p = 0.03$ ,  $p = 0.02$ ,  $p < 0.01$ , respectively). Opioid dosage in daily oral morphine equivalents was higher at T2 (median, 48 mg; interquartile range, 24-121) than at T1 (median, 39 mg; interquartile range, 13-100;  $p < 0.01$ ). In this study, laxatives showed a tendency toward decreasing ( $p = 0.09$ ). Drugs for chronic illness were used by 13% and 7% of patients at T1 and T2, respectively ( $p = 0.28$ ).

**Conclusions:** This study revealed that:

- 1) the PCT appropriately increased medications for symptom control, and
- 2) relatively few patients were still taking drugs for chronic illness at the time of PCT referral. We have planned a further study to investigate changes in patient-reported outcomes, and to reveal the burdens of polypharmacy and drug formula from a pharmacist-based perspective in the PCT.

**Abstract number:** P1-093  
**Abstract type:** Poster

## Development of a Conceptual Framework to Assess Quality in End of Life Care in Dementia: Contextual, Structural, Process and Outcome Variables

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**Aim:** The Supporting Excellence in End of Life Care in Dementia (SEED) research programme (<https://research.ncl.ac.uk/seed/>) aims to support professionals, both commissioners and providers, to deliver quality, community-based end of life care in dementia, through the development of a comprehensive approach to patient care delivery, known in the UK as an Integrated Care Pathway (ICP).

**Methods:** In order to identify indicators to measure the quality of this care, we developed a conceptual framework for assessing quality in end of life care in dementia, based on a review of existing palliative care literature, including the EAPC's White paper defining optimal care in older people with dementia. The framework provides a comprehensive overview of contextual, structural, process and outcome variables in patient care delivery, against which existing quality indicators for palliative care have been classified.

**Results:** The majority of existing quality indicators for palliative care measure processes of care ( $n=167$ ; 76%), which include assessment and referral processes, shared decision-making and patient/family information and education. Within processes of care, only a quarter of indicators appear to measure quality of actual treatment, support and care provided ( $n=41$ ). Results suggest that even fewer indicators measure outcomes of care ( $n=34$ ; 15%), which include physical comfort and psychological/spiritual well-being.

**Conclusion:** Overall, results suggest a need to develop quality indicators of end of life care in dementia that measure individual level person centred outcomes, in addition to indicators that assess the structure and processes of care.

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**Abstract number:** P1-094  
**Abstract type:** Poster

## Hospital End of Life Care: Lucky or Unlucky Dip?

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**Aim:** To assess and improve the quality of end of life care (EOLC) across a large two hospital NHS organisation by using questionnaire feedback from bereaved relatives. The collection of both quantitative and qualitative data enables targeted education and direct feedback to frontline staff. The questionnaire includes questions relating to the main findings of the UK Neuberger review of the Liverpool Care Pathway published July 2013.

**Method:** Questionnaires are sent to relatives 6 weeks after the patient's death in hospital. The questionnaire contains 'tick box' questions and a free text section. Data is collected and analysed to provide both an organisational overview and individual ward performance. Results are presented to executive leads, clinical teams and patient/ user groups.

**Results:** 436 of 1294 questionnaires were returned in the first year of the survey. Care was described as 'excellent' or 'good' in 72% of cases. 83% of respondents reported being treated sensitively. However, 29% did not recall any discussion about the plan of care at the end of life. 16% described help with eating and drinking as 'poor' and 13% said that information about pain relief and sedation was 'poor'. Only 46% strongly agreed or agreed with the

statement that there had been 'enough communication from ward staff'. Free text responses highlighted the striking variation between relatives' experiences and the distress caused to the bereaved when care at the end of life is poor.

**Conclusion:** This project gives a voice to the bereaved and shows that professionals want to listen and learn. Pride can be taken when care is delivered to an excellent standard but this survey exposed the unacceptable inconsistency of EOLC within the organisation. Hospital EOLC should not be a 'lucky dip' for patients hoping for excellence. The Trust has agreed actions to improve care and continues to seek feedback from the bereaved as one measure of quality improvement.

**Abstract number:** P1-095  
**Abstract type:** Poster

## Patients' Perception of Types of Errors in Palliative Care - Results from a Qualitative Interview Study

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**Background:** Medical errors have recently been recognised as a relevant public health concern and increasing research efforts have been made to find ways to improve patient safety. However, in palliative care, studies on errors are rare and mainly use quantitative approaches only.

**Aims:** To explore how palliative care patients perceive and what they think about errors in the palliative care setting and to generate an understanding of what an error in palliative care is from the patient's perspective.

**Methods:** 12 semi-structured face-to-face interviews with patients receiving palliative care were conducted by two interviewers, transcribed verbatim and analysed using qualitative content analysis.

**Results:** 7 interviewed patients were women and 5 were men, age ranged from 22-90 years (median age 63). 11 patients suffered from a malignancy, only one patient with a non-malignant diagnosis was included. Days in palliative care ranged from 10-180 days (median 28 days).

112 categories emerged within the 11 umbrella terms *definition*, *difference*, *type*, *cause*, *consequence*, *meaning*, *recognition*, *handling*, *prevention*, *person causing* and *affected person*. A deductive model was developed that assigned umbrella terms to error-theory-based factor levels (definition, type and process-related factors). 23 categories for *type* and 21 categories for *definition* were identified, each including 12 and 11 categories that can be considered as palliative care specific. On the level of *process-related factors* 3 palliative care specific categories emerged (*recognition*, *meaning* and *consequence*).

**Conclusion:** Compared to errors in other medical disciplines there are some aspects of errors in palliative care that may be considered as specific for that discipline. The explorative findings from the present study may be considered as a mental map on which further projects should assess single aspects or categories of errors in palliative care in more depth and detail in the future.

**Abstract number:** P1-096  
**Abstract type:** Poster

## Audit of Clinician Screening for Depression and Anxiety in Patients Admitted to a Hospice Setting

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**Background:** Depression and anxiety are prevalent in hospice settings. However, these disorders remain under recognised and under treated. The EPCRC recommends that all patients be screened for depression in this patient population.

In this institution no formal assessment tool is routinely employed to screen for these disorders. This audit examines clinician screening for depression and anxiety by review of patients' clinical notes for the first 72 hours of their admission. Results are then interpreted in line with EPCRC recommendations.

**Methods:** A retrospective medical chart review of sequential admissions was conducted over a ten week period from January to March 2014. The medical records were analysed according to documentation of mood using DSM IV criteria, previous psychiatric history, current psychotropic medication use and reference to a collateral history.

**Results:** Documentation of the assessment of mood does not occur routinely during the admission process. 48% of patients were screened on admission and a screening tool was not used.

**Conclusions:** The rate of documentation of mood assessment on admission needs to improve in line with EPCRC guidelines. The lack of a formal assessment tool is a likely contributing factor. Other reasons include both patient and clinician factors as highlighted by Breitbart.

The introduction of an admission booklet is proposed to address these issues. The inclusion of a formal assessment tool eg. the two question screening tool for depression, is suggested in order to increase documentation rates to the desired 100%. Payne et al has demonstrated a high level of sensitivity with this tool.

The audit will be repeated six months after the introduction of the admission booklet. It is hoped that clinician screening and documentation rates will have improved with these interventions.

**Abstract number:** P1-097  
**Abstract type:** Poster

## Do Hospitals Delivery 'Good' End of Life Care (EOLC) in the Absence of the Liverpool Care Pathway(LCP)? A Hospital Audit of the Documentation of EOLC for Dying Patients Following the Phasing out of the LCP and after the Introduction of a Locally Developed Tool

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The announcement in July 2013 of the phasing out of the Liverpool Care Pathway (LCP) caused anxiety within UK healthcare institutions. In part, the concern was that without a guidance document the principles of 'best care' for patients in the last days of life would be forgotten. In our hospital, use of the LCP fell dramatically after July 2013. It led to rapid introduction in January 2014 of a 'Key Elements' document (based on the principles of the LCP) on which clinicians could record prompted aspects of the care of dying patients. This paper presents an audit of documented care in our hospital before and after the introduction of the Key Elements document. The audit reviewed notes of deceased patients in December 2014 and in May 2015 respectively, for evidence of 7 'key' aspects of end of life care (EOLC). The aspects of care reviewed are consistent with the later published 'Principles of Care for the Dying Person'. The December audit reviewed 18 case notes. It showed 88% of notes had 5 or more 'key' aspects of good EOLC recorded. The May audit reviewed 16 case notes. It showed documented standards had not dropped with 87.5% of notes recording 5 or more 'key' aspects of good EOLC. However, recording on the Key Elements document was minimal (1 set of notes). At both time points, care interventions least recorded were spiritual care and some aspects of nursing care (e.g. mouth care). Our results suggest that some key aspects of EOLC were still being delivered in our hospital after effective cessation of the LCP. There is no evidence however, that clinicians used the new Key Elements to record their practice (although they may have used it as guidance). Lack of use of the new document may reflect paucity of knowledge or a reluctance to engage in its use. The audit highlights the difficulty of introducing new documentation into clinical practice, and we discuss possible problems with implementation. The audit is limited by small numbers and its retrospective nature.

**Abstract number:** P1-098  
**Abstract type:** Poster

## Forensic Attention to Detail: Lessons Learned from a Clostridium Difficile Outbreak in a Hospice Setting

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**Background:** Three different patients tested positive for Clostridium Difficile over a 3 month period. Each had attended a different clinical department within the hospice for their care. Enhanced fingerprint testing demonstrated the strains were indistinguishable PCR-ribotype 027 highly suggesting transmission within the hospice.  
**Method:** An incident meeting was held, chaired by Public Health England, to examine the root cause analysis in detail, and action plan agreed. An external infection control audit previously undertaken by Department of Public Health was reviewed. Overall score was 94% against a compliance score of 84%. Environmental ATP swabbing was undertaken by the community infection control team, 17/18 swabs passed the criteria for cleanliness, 18<sup>th</sup> swab was borderline fail.  
**Intervention:** Hand washing training and infection control is mandatory annually for all staff, students and volunteers, and is included as part of the new starter induction programme. Additional in-service training about Clostridium Difficile continues. Infection control policies were updated and specific infection control information leaflets devised and are now distributed to families. Housekeepers receive specific infection control training. Housekeeping establishment hours have been increased and cleaning schedules reviewed. Disposable hoist slings and slide sheets were purchased. Monthly audits of hand hygiene, waste, environment and sharps bins continue. Results are circulated to staff with action plans if necessary. An audit of Proton Pump Inhibitor and antibiotic prescribing was undertaken and results presented to clinical staff. HPV fogging was recommended and undertaken at the cost of £ 5000.  
**Outcome:** A score of 98% was achieved in the final external Public Health audit. The incident highlighted the importance of collaborative working between Hospice, NHS partners and Public Health England. Everyone is aware that infection control is everybody's business.

**Abstract number:** P1-099  
**Abstract type:** Poster

## Measuring the Impact of Palliative Care Using the Priorities of Patients and Carers to Refine a Service Evaluation Questionnaire

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**Background:** The delivery of optimal palliative care requires understanding of the patient and carer perspective. A service evaluation questionnaire, comprising nine questions and a free-text box, had been implemented across palliative care settings in Wales. The free text responses of 596 palliative care service evaluation questionnaires were analysed to examine the experiences, priorities and concerns of patients and carers. The emotional experience of care was central to the delivery of quality palliative care for patients and carers. It constituted a core practice referring to a positive change in attitude, affect or ability to cope following palliative care. These findings informed the AFTER follow-on study, testing and refining adaptations of the original questionnaire to reflect patient and carer priorities  
**Aims:** To refine the questionnaire to incorporate patient and carer priorities with the aim of implementing the revised questionnaire into practice.  
**Methods:** Thematic analysis was used to explore free-text questionnaire responses from 596 patients and carers. The resulting themes were used to inform initial questionnaire

refinement during an expert consensus day. In two further stages of refinement, semi-structured cognitive interviews were used with patients and carers (N=17) in receipt of palliative care to test the extent to which questions were relevant and understandable.  
**Results:** A number of changes were suggested by patients and carers, regarding the layout, wording and format of the questionnaire. Suggested changes arising from interviews were used to inform the final questionnaire revisions.  
**Conclusions:** This two stage study evidences the value of routinely collecting and analysing free-text data when measuring the quality of healthcare provision. The refined questionnaire provides a more efficient and pertinent route to feedback for patients and carers, and has been presented to the Palliative Care Implementation Board for their use.

**Abstract number:** P1-100  
**Abstract type:** Poster

## Does Bereavement Support in Intensive Care Units Meet UK National Guidelines? A Critical Care Staff Survey

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**Background:** Average mortality in Intensive Care Units (ICU's) in the UK is around 18%. Evidence is growing that a considerable proportion of bereaved family members develop prolonged grief, complicated by serious social, psychological and medical consequences. In 1998 the Intensive Care Society (ICS) published guidelines for bereavement care in the ICU emphasising its clinical importance.  
**Aims:** To investigate staff perceptions on bereavement care in a large UK tertiary referral ICU and to identify whether national recommendations are met.  
**Design:** We circulated an online survey using SurveyMonkey® to all critical care staff. The questions were mapped against the ICS guideline, specifically looking at staff training, support, audit, policy and facilities.  
**Results:** A total of 68 responses- 17 consultants(25%), 11 junior doctors(16%), 37 nurses(54%) and 3 allied healthcare professionals(4%) were collected. Table 1 shows the results highlighting lack of training, support and follow-up for relatives as major concerns for staff.

Table 1.	Yes	No	Unsure
Do you feel competent in speaking to children about bereavement?	15 (23.08%)	42 (64.62%)	8 (12.31%)
Do you think training about bereavement in the intensive care unit (ICU) would be useful?	62 (96.88%)	1 (1.56%)	1 (1.56%)
Does your ICU offer training in bereavement care?	5 (7.69%)	35 (53.85%)	25 (38.46%)
Do you think that facilities (e.g. relative rooms, meeting rooms) for bereaved relatives in your ICU ensure privacy and comfort?	15 (25.86%)	42 (72.41%)	1 (1.72%)
Does your ICU run a follow-up clinic for bereaved relatives?	3 (5.08%)	33 (55.93%)	23 (38.98%)
Does your intensive care unit have a care unit have a written bereavement policy?	15 (25.42%)	8 (13.56%)	36 (61.02%)

[Table 1]

**Conclusions:** We identified significant inadequacies in the management of bereavement care in our ICU, including failure to adhere to national guidelines. Staff highlighted the need for further training and support and a Palliative Care Social Worker has been appointed to develop a service in line with the national guidance.

**Abstract number:** P1-101  
**Abstract type:** Poster

## Implementing and Assessing a Caring for the Dying Care Bundle

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**Background:** Wide variations in the quality of care provided to people dying in acute hospitals exist. One potential solution is the implementation of care bundles. This work' aim is to investigate the effects of a care bundle for the dying on the quality of care delivered to dying people in acute hospitals, with quality referring to evidence-based, patient-centred, safe care.  
**Methods:** Approved by the local ethics committee, a quasi-scientific study was undertaken. The bundle was composed of an observation chart to monitor and respond to common symptoms, monitor family distress; facilitate prescribing. The primary outcome was whether pain score documentation improved as evidence-based recommendations. Secondary outcomes included whether the burdens of investigations were reduced after dying had been diagnosed and whether there was a difference in the opioid doses prescribed after dying was diagnosed in opioid-naïve people. Compliance with the care bundle was summarised.  
**Results:** A baseline audit was conducted to document usual practise (n=50). The pre and post proportion of people who had pain scores after dying was diagnosed were compared revealing significant differences between baseline and intervention ( = 27.9, p < 0.001). A significant difference in investigation numbers ordered after dying was diagnosed was observed ( $\chi^2 = 10.5$ , p = 0.001). No statistical differences were seen in opioid doses prescribed to those previously opioid- naïve and then commenced on opioids after dying was diagnosed. After the 6 months pilot, 76% (n=70) compliance with the bundle was noted, pain, breathlessness and family distress scores improving from 13%, 1% and 0% compliance respectively to >85% each.  
**Discussion:** This work, although preliminary, highlights that systemically implementing and objectively assessing care programs at the end of life can provide meaningful and measurable change.

**Abstract number:** P1-102  
**Abstract type:** Poster

## Implementing a Patient, Family Caregiver and Public Involvement Model for Palliative Care Research in Order to Influence Clinical Care, Policy and Funding

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**Background:** To achieve evidence-based, high-quality palliative care (PC), researchers need to collaborate with patients, family caregivers and the public (PPI) to plan, conduct and disseminate research that responds to patients' and families' concerns.  
**Aim:** To implement a PPI model in PC research to produce high-quality research with findings relevant to patients and families that influence clinical care, policy and funding.  
**Methods:** Patient advocates and researchers conducted nominal group technique research to establish how PPI in PC research should be delivered. Salient recommendations emerged and were used to iteratively develop a PPI model for implementation. The PPI implementation model was developed further and refined and agreed by consensus with an executive board of a leading PC research centre, which comprised clinical leads and international researchers. The implementation of the first two workshops was systematically reviewed in order to determine components essential to implementation.  
**Results:** An overall structure for the PPI model was developed and three variants were reviewed in order to agree on the final model. The components of the model were: Aim, outcome, structure, costs, and resources. Implementation review revealed that PPI model implementation depends on: PPI operational and strategic leadership from research staff; consistent relationship-based work with participants, which involves acknowledging the value of their clinical care experiences; a blended means of implementation (e.g., face-to-face and virtual platforms); sufficient resources to support implementation.  
**Conclusion:** Implementing PPI in PC research requires excellent leadership and a continuous professional relationship with all collaborators. These findings highlight the potential for optimising the value of clinical experiences within research settings in PC. Future research is needed to explore implementation, sustainability and impact of the model.  
On behalf of BuildCARE

**Abstract number:** P1-103  
**Abstract type:** Poster

## The Safe Prescribing of Medicines in a Hospice Setting

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**Background:** Within the hospice setting potentially harmful drugs are prescribed on a daily basis making it imperative that safe prescribing is a key aspect of palliative care.  
**Aim:** To highlight the importance of the prescribing standards outlined in the hospice's 'Medicine Policy' in addition to good prescribing practices identified by the hospice pharmacist.  
**Method:** With a view to minimising prescribing errors an audit of all currently prescribed medications was conducted over a two week period at the hospice. The audit standards were divided into two parts, one completed by the medical student and the second by the hospice pharmacist. Any standards not met were recorded daily; the type of error made was recorded as a tally and collated at the end of the audit period.  
**Results:** A total of 91 errors were recorded in part 1, and 24 in part 2. In part 1 41% (n=37) of the errors were a lack of instruction for priority of use when multiple medications were prescribed *pro re nata* (prn) for the management of one symptom. Within part 2, specific formulation details were also frequently missing from the prescription (67%, n=16). This was particularly problematic in the case of strong opioid liquids where different strengths are available. Other common problems included missing allergy status information, incorrect abbreviations of units, failure to complete the indications box and maximum medicine frequency not prescribed for prn medication.  
**Conclusion:** The audit results were presented to hospice staff to highlight areas for improving prescribing thereby reducing errors and potential harm to patients. This audit tool was quick and easy to complete and is an effective way of raising the awareness of good prescribing practice.

**Abstract number:** P1-104  
**Abstract type:** Poster

## Implementation of PaTz-groups in the Netherlands

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**Aims:** PaTz (palliative care at home) is an intervention to improve palliative care provision and strengthen knowledge. PaTz-groups consist of GP's and district nurses who work in the same area. They meet six times a year with an expert in the field of palliative care to discuss palliative patients. With funding from ZonMw Foundation, PaTz and Netherlands Comprehensive Cancer Organisation (IKNL) initiated 10 groups. The experience with the implementation of these groups will be used to initiate more PaTz-groups.  
**Approach taken:** We started with informing potential PaTz-groups. They had to meet the following requirements:  
• consist of at least 5 GP's and 2 district nurses  
• there had to be a chairman  
• groups were prepared to participate in a pre- and posttest  
All groups received training for the chairman. Furthermore they were supported in the first meeting.  
**Results:**  
• 16 interested parties came forward. 6 groups withdrew voluntarily. Main reason was lack of time.  
• 10 groups began in the period between April and September 2014 with a total of 67 GP's and 35 district nurses. The results of the pre- and posttest will be available in autumn 2015.  
**Lessons learned:** Contributing factors to the setting up of a group were:

- A doctor is the one who initiates the group
- The PaTz-meeting takes place during a regular meeting
- The group is already familiar with the expert in the field of palliative care.

**Abstract number:** P1-105  
**Abstract type:** Poster

## Psychosocial Interventions' Effectiveness at the Programme for the Comprehensive Care of Patients with Advanced Illnesses in Spain in 2013

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**Background:** The programme for comprehensive care of patients with advanced illnesses starts in 2008, as an initiative and funding support of 'La Caixa' Foundation, with the aim of adding quality and put in value the task of palliative care teams towards individuals (and their families) in end-of-life situation. The program has implemented 29 Psychosocial Care Teams (PSCTs), distributed among Spain, with a minimum of one team per region, and with 120 professionals, mainly psychologists and social workers. These teams aim at offering support to the existing palliative care services. They provide care to advanced patients and their families in regards to emotional, spiritual and social issues and contribute to their integral care.  
**Aims:** To assess the psychosocial interventions' effectiveness provided by PSCTs towards advanced patients and families.  
**Methods:** Quasi-experimental, prospective, multi-centred, one group and pre-test/post-test study. The evaluation of patients and relatives (individuals) taken care by PSCTs from October 1<sup>st</sup> 2012 to September 30<sup>th</sup> 2013 was included. The assessment of psychosocial interventions' effectiveness was performed after the basal visit and for 4 follow-up visits. The dimensions observed included: mood, anxiety, unease, adaptation and suffering, for patients; and unease, anxiety, depression and insomnia, for relatives.  
**Results:** 10.471 advanced patients and 18.131 relatives have been assessed during the period of study. 32.674 and 44.506 visits, respectively, were performed. There is a significant improvement in the following areas:  
1) evaluation performed during the 4 follow-up post basal visits;  
2) all variables for patients;  
3) anxiety and emotional unease variables for relatives.  
**Conclusion/discussion:** The PSCTs provide effective interventions and contributes to improve the emotional symptoms and unease of patients and their families.

**Abstract number:** P1-106  
**Abstract type:** Poster

## Quality of Information from Acute Hospitals to a Hospice

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**Background:** Recent experience in a hospice appears to show that discharge letters received from acute hospitals often lack a sufficient clinical summary and drug information to provide optimal continuity of care and good symptom control.  
**Aim:** To assess the completeness and reliability of information supplied by acute hospitals.  
**Methods:** A retrospective analysis of patients admitted to a hospice from acute hospital trusts was over 8 months was performed. The Royal College of Physicians Hospital Discharge Record Keeping Standards Audit Tool was adapted and used. The presence or absence of a discharge letter, drug information, including Patients Own Drugs (PODs) and indications were audited and discrepancies between these were noted. The adequacy of clinical summaries and continued drug recommendations were also reviewed.  
**Results:** Nineteen referrals were received (8 hospitals); 16% (3) did not have a discharge letter. In the 16 letters received, 4 clinical summaries were inadequate, 4 were missing relevant investigation results, and one did not have a list of drugs. In 12 cases, drugs were listed in the letter and a photocopy of the corresponding drug chart was supplied. However, only 4 of these matched and 28 discrepancies were found in the remaining 8. Of the 8 patients with PODs, 3 did not correspond with the discharge letter and/or drug chart. Indication for medications was not clear in 53% (8) patients.  
**Conclusion:** Patients were frequently transferred to the hospice with inadequate information. Essential clinical information was missing or not supplied in 37% (7 patients). Drug discrepancies were found and drug indications and test results were missing or not forwarded. The omission of such information impacts on continuity of care and is detrimental to optimising symptom control. Our efforts are now focused on communicating these audit findings to the Palliative Care Teams in our referring hospitals to improve quality of information on transfer.



**Abstract number:** P1-107

**Abstract type:** Poster

## Are COPD Patients Receiving Adequate End of Life Care?

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**Aim:** To assess our current practice for patients with COPD (Chronic Obstructive Pulmonary Disease) against recent end of life care components in NICE guidelines.

**Background:** Half of the patients known to our hospice have chronic non-malignant disease. COPD makes up a significant proportion of these patients. There has been an interest in developing our respiratory service further. However an audit of our current practice needed to be done first to allow the service to be appropriately developed.

**Design and method:** All patients on the case load in 2013 at our Hospice were identified. All notes were then reviewed.

**Results:** 65 patients were known to us in 2013. The majority were referred from the respiratory care team, the local hospital and local General Practitioners. Multiple criteria were cited as the reason for referral; most common reasons being symptom control and psycho-social support. 86% of patients had evidence of advanced care planning in the notes and 75% of patients were aware that their disease was life limiting. 72% patients had a documented preferred place of death discussion. 71% of patients had documented evidence of a psychological review, only 45% had evidence of a physiotherapy review and 42% had an occupational therapy review. 45% of referrals did not meet Gold Standards Framework prognostic indicators for COPD. However 69% of referrals did note other markers suggesting patients may be nearing the end of their life. Therefore 30% of all referrals did not show any indicators that a patient may be nearing the end of their life. There were only 62 day care contacts recorded which suggests that these patients are not utilising our day care services.

**Conclusion:** Although we provide a good service for many of the end of life care components there are key areas that could be further developed; notably occupational therapy and physiotherapy input as well as an improved day unit service.

**Abstract number:** P1-108

**Abstract type:** Poster

## An Audit of Depression Screening in a Hospice Inpatient Unit

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**Background:** Depression is common, often undiagnosed and untreated in palliative care patients. The aims of this rolling audit have been to assess if patients in a hospice Inpatient Unit (IPU) have documented depression screening and secondly, a documented management plan if diagnosed with depression, according to locally agreed standards.

**Methods:** A retrospective audit of consecutive admissions to a 10 bedded adult hospice IPU has been undertaken annually from 2007 to 2014. Evidence of informal depression screening was sought in a baseline audit in 2007. Following this, the Hospital Anxiety and Depression Assessment Scale (HADS) was introduced into the clinical notes as the formal screening tool and completion of the HADS was assessed in subsequent audits.

**Results:** A total of 289 inpatient admissions have been audited between 2007 and 2014 with between 23 and 61 hospice inpatient admissions having been audited annually. In the initial audit only 40% (12/30) of patients had either informal depression screening or were deemed unsuitable for screening. Only 1 patient, of those diagnosed with depression during admission, had a documented management plan. Introduction of the HADS has improved practice. In subsequent audits, between 70% and 90% of inpatients have either been screened using HADS or were documented as being unsuitable for screening and 100% of patients diagnosed with depression had a documented management plan.

**Conclusions:** The introduction of the HADS in clinical practice and annual audit of its use within a hospice IPU has been associated with improvement in the rate of depression screening and documentation of depression management. This more proactive approach should result in earlier diagnosis and treatment of depression which may impact on quality of life. Additionally, it is the experience of clinicians within this hospice IPU that the HADS promotes holistic care and can act as a 'gateway' to more open discussions with patients and families.

**Abstract number:** P1-109

**Abstract type:** Poster

## TACT: What Impact Does Research Partner Involvement Have on the Working Practices of a Clinical Trial Unit and Academic Research Centre?

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**Background:** From 2005 a clinical trials unit has involved lay representatives ('Research Partners-RPs') as members of trial management groups (TMGs), reviewing documents and chairing and presenting at sub-committees. However, the impact of their work has not been routinely examined. The TACT study was conducted to investigate the input and impact of RPs to ensure the best possible working partnership between the trials unit and the public is achieved.

**Method:** Semi-structured interviews were conducted with 10 RPs and eight staff members to explore RPs' input; documents from TMGs, emails and relevant outputs were analysed using a Framework approach to analyse the impact of their work.

**Results:** RPs and members of staff understood the RP role to be an advocacy role for patients. RPs spoke of feeling welcomed into the trials unit and most were happy with their level of involvement; however others made more negative points reflecting a perceived bias in the unit's tendency to use more experienced RPs, the RP role being a funding requirement that is tokenistically implemented and the need for greater monitoring and support. Staff members were unclear about the degree to which RPs should be involved in their work. While there was a general recognition that greater commitment was required of them in the

RP initiative, it was evident that time pressures and stresses were constant barriers to achieving this.

Analysis of RP impact led to generally unfavourable results. Evidence of RP input in TMGs did not equate with subsequent actions and contributions in the centre's outputs appeared to be minimal.

**Recommendations:** Members of staff require further training to fully understand how RPs should be incorporated into the units work. They also need greater support to enable them the time to fully engage with the initiative. Regular auditing of the RP role needs to be developed to ensure that RPs are being involved as fully as possible in all appropriate stages of the units work.

**Abstract number:** P1-110

**Abstract type:** Poster

## Evaluation of Hospice Care Service in Malignant and Non-malignant Terminal Patients in a Hospice Care Unit in Taiwan

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**Background:** Hospice care had been in practice for 30 years in Taiwan. However, it was not until 5 years ago that non-malignant terminal patients were included. Thus, not only the general public need to be made aware of this change, but medical staff members also need more experience in caring for terminal patients with non-malignant disease.

**Aims:** To investigate if current care provides benefit to both malignant and non-malignant patient.

**Methods:** This study consisted of 299 terminal cancer patients who were admitted to the hospice ward during August of 2013 to June of 2014. We evaluated clinical outcomes of patients one week after admission and then weekly until patient's death by using Support Team Assessment Schedule (STAS). For each category, the intensity of the problem was scored on a 5-point scale (0-4), higher score indicating increased severity.

**Results:** Comparing to patients with non-malignant disease, cancer patients had significant higher level of pain, sleep disturbance, lymphoedema, depression, and anxiety ( $p < 0.05$ ) at the first STAS assessment. However, non-malignant patients had higher level of dyspnea ( $p = 0.03$ ) and poorer insight on his/her prognosis ( $p < 0.001$ ) as compared to cancer patients. On day 14 after admission, there was no significant difference between the scores of cancer and non-cancer patients. ECOG score and length of admission were not significantly different between these two groups.

**Conclusion / Discussion:** Non-malignant patients were less prepared and had poorer insights on his/her prognosis in the hospice care unit. The term 'terminal' in non-malignant disease may be hard to define. In addition, advance care planning is not popular in Taiwan, hence life-and-death issue is usually not discussed in time. Medical staff members should be obligated to fully inform non-malignant terminal patients of their disease course and prognosis, allowing patients enough time to cope with their condition and make important decisions.

**Abstract number:** P1-111

**Abstract type:** Poster

## Differences in Medication Prescription between Hospitals, Hospices and Home Care in the Last Week of Life: Results from the MEDILAST Project

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**Background:** Medication management in the last phase of life is often challenging. Little is known in this context about the differences in medication prescription between care settings.

**Aim:** To compare medication prescription between patients dying in hospitals, hospices and home care in the last week of life.

**Methods:** Multi-center retrospective study of clinical records from patients with chronic conditions who died in the wards of geriatrics, oncology, neurology, cardiology and respiratory medicine of 3 academic centers and 7 peripheral hospitals, 3 high care hospices and 32 primary care practices in the Netherlands.

**Results:** Records from 178 patients were reviewed, of whom 84 (47%) were men. Mean (SD) age at the time of death was 74 (13) years. No differences were found between settings for gender and age. The mean (SD) number of medications prescribed in hospitals, hospices and home care were 14 (5), 11 (4) and 10 (5), respectively ( $p < 0.001$ ). The three most prescribed types of drugs varied per setting. In the hospital 77% of patients received opioids, 69% antithrombotic agents and 65% antacids; in hospices 80% sedatives, 77% opioids and 62% laxatives; and in home care 72% opioids, 61% sedatives and 52% antacids. Decision-making around the use of antithrombotic agents in hospitals revealed the use of antithrombotic protocols.

**Conclusion:** Medication prescription seems to focus on symptom control in the three settings. However, medication with preventive purposes like antithrombotic agents, antacids and laxatives frequently add to the medication burden of dying patients, especially in hospitals. Clinicians could reduce this burden by a continuous reassessment of prognosis. Research is needed to assess the harm/benefit of preventive medication prescription in this population.

**Source of funding:** This study was carried out within the framework of the MEDILAST project (Medication Management at the End of Life), funded by a grant of the Dutch government (ZonMW 1151.0036).



**Abstract number:** P1-112  
**Abstract type:** Poster

## The Quality of Palliative Care in the Netherlands

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**Background:** In recent decades, palliative care in the Netherlands has developed significantly, in part thanks to supporting government policies. Many services and quality tools have been put in place, like hospices, guidelines, consultation and education.  
**Aim:** What can we say about the quality of palliative care in the Netherlands?  
**Method:** Dutch literature, including 'grey literature' and websites from 2008-2013. If there was no recent literature or if it had added value in order to describe the history, we also used literature before 2008.  
**Results:** There are no reference guidelines to assess the quality of palliative care in The Netherlands: benchmarks do not exist or are not being widely adopted. We have therefore focused on the identification of obstacles to the development of high quality of care. Research has shown the following:  
In 30% of cases, more frequently in cases of non-oncological disease compared with oncological disease, the primary care physician does not recognize impending death in the last three months (of the patient's life).  
In 22% of the cases, the dying phase is not recognised. This can lead, to unnecessary interventions. - Treatment goals remain aimed at curative care for too long (22% in the last 3 months, 6% in the last week).  
Symptom relief is not always enough : 28% of terminal cancer patients experience unbearable suffering.  
Palliative sedation does not always work well, according to nurses involved (42%), in particular in the area of medication policy, communication and cooperation agreements. In the last month of life, two out of three patients have to deal with one or more transfers, often to the hospital.  
**Conclusion:** General statements about the quality of palliative care in the Netherlands are not possible. Research points to problems that require attention. Development of a comprehensive system which maps and records the quality of palliative care in the Netherlands is desirable.

**Abstract number:** P1-113  
**Abstract type:** Poster

## Palliative Care Professionals' Views on Guidelines in Palliative Care

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**Background:** There is an increasing number of guidelines in palliative care. To foster implementation of these guidelines, knowledge of barriers and facilitators of potential users is necessary.  
**Aims:** To describe barriers and facilitators for the use of evidence based guidelines of palliative care professionals in Germany.  
**Methods:** Web-based online survey with professionals from the German Palliative Care Association in summer 2014.  
**Results:** 1031/4786 respondents (20%), 65% female, median age 50 years (range 24-79), professional experience median 22 years (range 0-50), 55% physicians, 30% nurses, 14% other professions, specialisation in palliative medicine/care 73%. Barriers to guideline use were: guidelines not up to date (73%), reluctance to change own routine (58%), too many guidelines (49%). Impact of guidelines on current practice 79% (physicians > nurses). Main barriers for guideline use: lack of knowledge 46% (nurses > physicians), lack of motivation 9%, lack of expectation of improved treatment 20%. Positive attitudes towards palliative care guidelines: improve quality of symptom control (97%), care based on up to date evidence (96%), make a difference in patient care (91%). Recommended measures for implementation (>90%) were information from relevant associations, standard operating procedures, publications, and integration in undergraduate training.  
**Conclusion:** Palliative care professionals' attitudes towards guidelines are quite positive. Special attention should be given on information transfer and on nurses during the implementation process in order to increase adoption of guideline recommendations.

**Abstract number:** P1-114  
**Abstract type:** Poster

## Performance Measurement and Quality Improvement in Palliative Care: Toward a Minimum Data Set for a Region in Ontario, Canada

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**Background:** The Regional Hospice and Palliative Care Program coordinates and integrates the delivery of hospice and palliative care services for the entire region, working closely with the various service providers to ensure access and quality.  
**Aims:** To establish palliative care standards and to create (priority) performance indicators leading toward a minimum data set for performance measurement and quality improvement in the region.  
**Design:** Following a scoping exercise and a review of existing standards and performance indicators, a modified Delphi-approach was utilised to identify (priority) indicators along four domains: access, capacity, coordination and outcomes/quality. Further stakeholder consultation was undertaken prior to implementation.  
**Results:** Forty palliative care standards were adopted and 56 related performance indicators (with numerator and denominator) created, leading to 11 priority indicators across all domains. Pilot testing and technical support yielded initial data and feedback from 21

provider organisations across all sectors from home to hospitals and hospices (baseline; response rate 66%) in the region. Gaps have been detected in several areas including:  
· health care provider education/volunteer training;  
· transition management/wait times; and  
· advance care planning/communication.  
**Conclusion:** The project has established a set of palliative care standards and linked (priority) indicators, tested the feasibility of an electronic data collection mechanism and discovered gaps that could lead to a quality improvement system via minimum data set for the region and beyond. The standards and respective (priority) indicators will be presented.  
**Funding:** This project was supported by funding from the Local Health Integration Network.

**Abstract number:** P1-115  
**Abstract type:** Poster

## Vialon Cannulas for Subcutaneous Infusion of Drugs to Terminally Ill Patients in Hospice Home Care

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**Background:** In Poland metal butterfly needles are commonly used for subcutaneous infusions in palliative care. This way of infusion is particularly helpful for patients with advanced age to give hydration or drugs for pain, agitation or nausea. In many cases it helps to avoid hospitalization, secures patient comfort and is easy to perform.  
**Aim:** Prospective study of home care patients requiring continuous infusion of drugs, to estimate tolerability of Vialon cannula (BD Saf-T-Intima) compared to metal butterfly needles. To determine the survival time of cannula or butterfly, skin reaction, influence of the type and quantity of drugs on side effects occurrence, viability and satisfaction of patient and personnel.  
**Material and methods:** The study was performed between May and October 2014. Data were collected on 20 home care cancer patients (age 77±9) from the time of insertion of the first needle or cannula to the time of the replacement. The replacement of the cannula or butterfly was performed as often as it was necessary, but no more often than 3±1 days. After 2 weeks of the study the butterfly needle was changed to Vialon cannula to check survival time. For each patient we used a form to record demographic data, site of insertion, side effects, reasons for removing and the dose of drugs.  
**Results:** The analysis showed that duration of the subcutaneous site was significantly longer with the Vialon cannula (7 vs 3 days). Both patients and nurses preferred the Vialon cannula because it did not need to be changed as frequently as butterfly needle, had less side effects (Vialon cannula 15% vs butterfly needle 85%) and higher level of patient and personnel comfort ('very satisfied' 99%).  
**Conclusions:** Vialon cannulas were very well tolerated by patients and nurses. It is a good alternative for administration of medications by sc infusion in terminally ill patients because of its survival time and fewer skin reactions.

**Abstract number:** P1-116  
**Abstract type:** Poster

## How Well Are Dying Patients Cared for in Acute Hospitals in England? A Summary of the Latest National Care of the Dying Audit - Hospitals, England 2013/14 (NCDAH) Results

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The quality of end of life services is a suggested indicator of the quality of all health care provision. NCDAH provides data re:standard of care delivered to imminently dying patients.  
**Aim:** Report upon care provided to dying patients and their relatives to highlight areas for improvement in clinical practice and influence policy/funding/research agendas.  
**Method:** Retrospective clinical audit of organisational aspects of care and Clinical data from 6580 patient records for May 2013 from 131 Hospitals (H).  
36H (27%) captured 858/2313 (37% response) bereaved relatives' (BR) views via Care of the Dying Evaluation questionnaire.  
**Results:** Median age 82; cancer diagnosis 23%(1546); female 51%(3332).  
**Organisational**  
7 day access to specialist palliative care service (SPCS) in 28H (21%)  
No education/training provision in 24H (18%)  
No Trust Board (TB) representation in 61H (47%)  
No Audit in 57H (44%)  
Processes to capture BR views in 61H (47%)  
**Clinical**  
Decisions and assessments routinely recorded eg  
Recognition of dying recorded in 87% (5722) cases  
≥5 patient assessments in last 24 hours recorded in 82% (5409) cases  
Exceptions: Clinically Assisted Nutrition 45% (2563)/Hydration 59% (3351)  
Communication of decisions more likely undertaken with relatives than patients eg  
Capable patients: 46% (1063/2327\*)  
Relatives: 93% (5313/5722\*)  
Least routinely recorded  
Spiritual needs assessment: Capable patients: 21% (715/3391\*); Relatives: 25% (1623/6575\*)  
Care of the body after death: 46% (3037)  
**BR Views**  
Most reported patients were 'always' treated with dignity/respect by doctors (66%/535\*), nurses (70%/577\*)  
BR felt adequately supported (76%/610\*)  
**\*Reduced sample**  
**Conclusions:** Organisational processes to include: 7 day access to SPCS/Education/Trust Board representation/audit. Clinical decision documentation and communication to patients and relatives could be improved. Bereaved relatives views generally positive, but a significant minority reported negative perceptions of care.

**Abstract number:** P1-117  
**Abstract type:** Poster

## Measuring the Quality of End of Life Care for Patients with Advanced Cancer on the Intensive Care Unit

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**Background:** Outcomes for critically ill cancer patients have improved; hence intensivists are increasingly willing to initiate a trial of Intensive Care Unit (ICU) therapy. Yet ICU mortality remains high. Quality indicators for end of life care (EOLC) on ICU were proposed by the American College of Critical Care Medicine (ACCCM).  
**Aim:** To explore EOLC provision for patients with cancer who transitioned to EOLC on ICU.  
**Methods:** Retrospective note review of medical patients admitted to a cancer ICU over six months. Patients who transitioned from active ICU to EOLC were identified. Quantitative and qualitative data analyses were undertaken, with respect to ACCCM quality domains for EOLC. Admission characteristics were compared between EOLC and active treatment groups to identify factors predictive for EOLC transition.  
**Results:** 38/85 (44.7%) patients transitioned to EOLC on ICU. Of the EOLC group: 56.2% saw the palliative care team, and symptom control was achieved in 79%. When decisions regarding transition to EOLC and resuscitation were made, 51.4% and 40.5% patients respectively were too unwell to discuss these. EOLC transition was discussed with 97.3% relatives. 76.3% of the EOLC group died on ICU, with preferred place of death known in 10%. Psychological, welfare or spiritual support was offered to 29%, 21% and 37% respectively. Qualitative analysis identified themes:  
1. Achieving consensus to initiate EOLC discussions;  
2. Concomitant prognostication and managing uncertainty;  
3. Shared oncology and ICU decision making;  
4. Integrative palliative care;  
5. Family-centred versus patient-centred care.  
Baseline performance status and prognosis were potential predictive factors for EOLC transition, but documented in only 40% and 16.5% of all patients respectively.  
**Conclusion:** Tools and guidance to support delivery and documentation of high standards of EOLC are needed. Earlier advance care planning whilst patients are well enough may enhance individualised EOLC on ICU.

**Abstract number:** P1-118  
**Abstract type:** Poster

## Managing Paracetamol in Hospice Inpatients: Does Having a Structured Protocol Improve Patient Safety and Length of Stay?

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**Background:** Whilst paracetamol is considered a safe and effective procedure for managing malignant ascites, there is wide variation in practice across sites, particularly regarding rate and duration of drainage and management of hypotension. A 2010 Cochrane Review demonstrated a paucity of evidence regarding an optimal approach. A single study (2002) involved a 6-hour free drainage protocol for hospice and hospital inpatients, reporting only one adverse event.  
**Aims:** To assess whether introduction of a standardised protocol for ascitic drainage reduces drainage time/length of stay, improves patient safety, and is acceptable to hospice nursing staff.  
**Method:** Retrospective notes review of 12 paracetamol episodes in the year prior to protocol implementation and 11 episodes in the year post-protocol implementation. Written free-text survey to nursing staff.  
**Results:** Average length of hospice stay decreased after protocol implementation (9.2 days pre-protocol compared to 5.4 days post). Average length of drainage time decreased after protocol implementation (23.6 hours pre-protocol compared to 16.7 hours post). The frequency of hypotensive episodes was unaltered. Frequency of blood pressure measurement during drainage, and staff management of hypotension, became more consistent.  
The surveyed nursing staff found the protocol acceptable, identifying both positive (safety, accountability) and negative (paperwork, time) implications.  
**Conclusion:** There is minimal research to support an optimal approach to paracetamol in a hospice setting. Implementation of a protocol does appear to reduce average duration of drainage and length of stay in uncomplicated patients, with no adverse effect on safety. Further research on larger sample sizes is warranted.

**Abstract number:** P1-119  
**Abstract type:** Poster

## Medications for Symptom control in the Dying Person: An Analysis of the Use, Choice, Dosage and Route of Drugs Used to Manage the Dying Phase in Residential Patients in Community, Hospice and Hospital Settings

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**Background:** Appropriate use of medications is essential to ensure adequate symptom control for the dying. This may vary across different settings due to a variety of factors. Clinical practice generally favours the subcutaneous route for medication delivery in the dying; however, the prevalence, and use, of alternative available routes has not previously been reported.

**Aim:** To analyse the use, dosage, choice and route of medications used to manage symptoms in the dying.  
**Method:** A prospective and retrospective, multi-professional case note analysis of deaths in community, hospice and hospital settings over a two month period in 2014.  
**Results:** Data for 277 deaths were recorded. Most were female (n=147, 53.1%), aged 71-80 (n=76, 27.4%) with cancer (n=205, 74%). Most were hospice based (n=174, 62.8%), followed by hospital (n=86, 31%) and community settings (n=17, 6.1%). Specialist Palliative Care (SPC) was involved in the majority (n=245, 88.4%). Continuous subcutaneous infusion (CSCI) syringe driver medications were used in 207 (74.7%). In those receiving CSCI medications, opioids were used in most (n=187, 90.3%); morphine was used most commonly (n=59, 29.2%). The median equivalent oral morphine dose at death was 60mg/24hr (IQR: 30-180mg/24hr). Common CSCI medications were midazolam (n=162, 78.3%), glycopyrronium (n=62, 30%) and levomepromazine (n=60, 29%). Median doses were higher compared to the UK National Care of the Dying Audit Hospitals (NCDAH) 2014. Thirty four (12.4%) patients had an alternative medication route (e.g. intravenous (IV) access, percutaneous endoscopic gastrostomy (PEG) tube) in-situ at death.  
**Conclusion:** This analysis provides quantitative data about medication use in the dying across a variety of settings and highlights some differences compared to the NCDAH (which may reflect the complexity in SPC). Further guidance on the use of other medication delivery routes in the dying is required, as several patients had IV and PEG access at death.

**Abstract number:** P1-120  
**Abstract type:** Poster

## Mapping and Reducing Polypharmacy in a UK Hospice Inpatient Setting

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Polypharmacy is the prescribing of multiple medications to one individual. The UK's Kings Fund report (2013), 'Polypharmacy and medicines optimisation', recommends research to improve medicines management. There are no guidelines specific to the field of specialist palliative care, where medication regimens likely pose a significant burden on patients, prescriber and service (cost and manpower). Yet, the extent of 'inappropriate polypharmacy' in palliative medicine is unknown.  
Our project aim was to map the levels of polypharmacy and to implement strategies to reduce this in a UK hospice inpatient unit (27 beds).  
Baseline data for the number of regular medications, tablets and volume of liquid medication was collected for a total of 41 consecutive inpatients. Weekly point prevalence data (number of medications, tablets and liquids) was collected for each patient on one ward (14 beds) for 10 weeks prior to implementing a series of 'tests of change'. These focused on education and guidelines on the use of paracetamol, laxatives and knowledge of dose sizes. Post implementation, weekly point prevalence data continued for 14 weeks. Counter balance measures were employed which included monitoring levels of 'as required' medication, mls of liquid medication and point prevalence data from the control ward. Test of change was assessed by Shewhart charts and interrupted time series analysis.  
Baseline medication levels observed for the patients at discharge were a mean of 9.5 medications per patient, 15.1 tablets and 60mls liquids. Post intervention data demonstrates that polypharmacy reduced in this patient population by 16%-number of medications, 25%-number of tablets and 30%-volume of liquid medicines.  
Education and the use of hospice specific guidelines has succeeded in reducing polypharmacy levels in this population of patients. The generation of accredited guidelines on polypharmacy specific to the field of palliative medicine and its care settings are recommended.

**Abstract number:** P1-121  
**Abstract type:** Poster

## Percutaneous Cervical Cordotomy for Mesothelioma (and other Cancer)-Related Pain: Is it Effective and Safe, and is Continued Commissioning Warranted? (Results of the UK National Registry)

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Studying mesothelioma-related pain is essential: in the UK, mesothelioma incidence is rising and expected to peak around 2020. It is often associated with difficult, even refractory, pain syndromes: this is acknowledged by the UK National Mesothelioma Framework which suggested that patients should have access to cordotomy as a palliative intervention. Percutaneous cervical cordotomy (PCC) involves creating a radiofrequency lesion in the spinothalamic tract in the cervical spinal cord. It has utility in unilateral pain syndromes where an acceptable balance between side effects and analgesia has proven difficult. There is great inequity in provision: only 4 sites across the UK perform more than 10 per year. Though a systematic review of the sparse literature indicated PCC might be effective and safe, it did not provide evidence to support continued provision. Clinical consensus was reached on the place of PCC in the clinical pathway in the UK and resulted in the launch of a national registry in January 2013.  
Up to August 2014, the registry has accrued 87 cases from 4 practitioners. Interim analysis indicated effectiveness: 62% of patients reported in excess of 90% improvement in pain, with 56% having no background pain and 59% no breakthrough pain at discharge. Qualitative comments support these findings, with 89% stating they are pleased. The effect is sustained well throughout follow-up, with 51% having no background pain and 52% no breakthrough pain at follow-up. Adverse effects at follow-up include dysaesthesia (21% mod-severe), mirror pain (15% mod-severe), limb weakness (36%), hypotension (8%) and headaches (11%).  
The first full analysis of outcomes for the first 100 cases will be presented. We will reflect on what this means for practitioners (e.g. maintaining competency) and consider the impact on and future approach to continued commissioning of UK PCC services. Networking with interested colleagues will clarify whether an international registry is warranted.

**Abstract number:** P1-122  
**Abstract type:** Poster

## Developing Palliative Care Knowledge and Skills in a Heart Failure Team: Does it Improve Quality of Care Delivery?

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**Background:** Over the past few years, the local Heart Failure (HF) team has improved their palliative care knowledge and skills, particularly developing confidence with prognostication: this process started with joint working between the specialist palliative care (SPC) and HF teams on a 'Principles of good palliative care' project in 2010. Prior to the project, the HF team undertook a documentation audit to review their management of the palliative care needs of their patients. Teaching sessions followed, with subsequent time to imbed into practice the principles of good palliative care, including optimising communication with primary care regarding needs and likely prognosis.

**Aims:** We set out to understand better whether the HF team's journey resulted in good quality palliative care delivery to their patients.

**Methods:** We first closed the audit loop to ascertain whether the clinical records evidence any change in practice, and then set up a sequential focus group study with the HF team to understand in what ways their practice has changed and how this impacts on quality of care delivery.

**Results and discussion:** Qualitative analysis is ongoing but seems to suggest significant changes in how the team now approaches and coordinates patient care, and provides insight into how this translates into quality of care. We will present the findings of the audits (pre- and post intervention) as well as the final analysis of the focus group study. We will specifically consider how team culture influences quality of care delivery.

**Abstract number:** P1-123  
**Abstract type:** Poster

## A Swedish National Palliative Care Plan (Swe-NPC): A Pilot Study

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**Background:** A Swedish national palliative care plan has been developed evolving from The Swedish Register of Palliative Care, National Guidelines for good palliative care at the end of life, National Programme for Palliative Care and the Liverpool Care Pathway for the dying patient. Parallel to the contribution of a multi-professional national reference group the care plan is being tested in clinical practice.

**Aims:** To test the feasibility, reliability and validity of Swe-NPC in different clinical settings.

**Methods:** Two municipalities volunteered to pilot test the care plan for three months in four long term care facilities including a home for people with dementia and a county palliative home care setting. Employees (n= 146) received a two-day training session, and face to face support from the project leader once a week during the trial. Data consisted of field notes from every contact, three taped-recorded focus group interviews with staff (n= 18) from the settings, and a summary of the review of Medical records of patients on the Swe-NPC. Data were analysed using both quantitative and qualitative content analyses.

**Results:** In total 50 patients had been on Swe-NPC. It was found to constitute a clear and structured assistance in planning care for patients along the palliative trajectory, even though it requires adjustment for the very old patients. Also the pilot study raised questions about which information staff was required to give to patient and family, and the kind of knowledge, education and procedures needed to make Swe-NPC sustainable in everyday practice.

**Conclusion:** Swe-NPC is a promising tool for improving the care of patients along the palliative trajectory. It does however need further testing in for example, acute care, and a stronger inclusion of a variety of patients' and families' perspectives.

**Abstract number:** P1-124  
**Abstract type:** Poster

## Systematic Use of a Quality Registry for Palliative Care Development

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**Background:** Systematic quality improvement of care at the end of life is still scarce. The regional palliative care (PC) service is organised as one department with eight services that comprises 80 hospice beds and 300 sites for advanced home care covering a population of 1.2 million inhabitants.

**Aims:** To systematically compile and report quality indicators through the Swedish Palliative Care Register (SPCR) for the eight PC services and to visualise and communicate the results to all units and staff in order to increase quality of care for both the units and the department overall.

**Design:** Data were retrieved from registrations in the SPCR. The quality reports covered twelve indicators including aspects of medical information to the patient and relatives, patients' wishes of place of death, symptom assessment and control and pressure sores. Since February 2014 all units have been presented with theirs and the others quality scores in the form of spider charts once a month.

**Results:** 98% of the patients were registered after death in the SPCR. Average quality scores from January to September 2014 were compared with average scores for 2013 in the department overall. The compliance rate of 10/12 indicators showed some increase. The average quality scores for all 12 indicators showed a slight increase, 72.6 % to 75.9% (n.s.). However, for individual units major improvements occurred while no decrease was found. Possible improvement strategies behind the positive changes will be further analysed and a comparison including the full-year results for 2014 will be presented.

**Conclusion:** Our experience is that a structured use of SPCR provides support the development of care and provides opportunities for internal and external benchmarking. As secondary effects we have seen better quality of reporting. Low quality scores helped us to prioritising topics for teaching and training. The observed follow-up time is short and the positive trends must be interpreted with caution.

**Abstract number:** P1-125  
**Abstract type:** Poster

## Caregivers' Perception of Palliative Sedation: A French Opinion Survey

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**Background:** In end-of-life palliative care, appropriate medications may be ineffective in relieving symptoms. When this condition leads to intolerable suffering, palliative sedation (PS) must be considered. Although guidelines have been developed in France, ethical controversies and inappropriate requests appear to exist in clinical practice. We hypothesised that this situation is due to caregivers' inadequate knowledge.

**Objective:** We aimed at investigated caregivers' knowledge, experience and feelings related to PS.

**Methods:** We conducted a survey in a French University hospital. Caregivers from departments including dedicated palliative-care beds were asked to fill in a questionnaire composed of 6 items concerning PS definition, experience and emotional impact.

**Results:** 160 questionnaires were completed by nurses (39%), physicians (37%) and nursing assistants (18%). Of them, 38% had been involved more than ten times in PS. 23% knew the consensual definition of PS and 50% made a clear difference between PS and euthanasia. 24% of caregivers felt unsettled by PS practice. Crossing data showed that less caregivers were destabilised when they made a clear difference between PS and euthanasia than when they did not (18% vs 36%, p < 0.025). There was no statistical relationship between the experience in practice of PS and its emotional impact. Thinking that 'the goal of PS is patient's relief' rather than 'a decrease in consciousness' was associated with a better distinction between PS and euthanasia (73% vs 55%, p < 0.05).

**Discussion:** The present study showed that PS definition, indication and purpose were unclear in a raised awareness population. These results support the idea that PS remains a complex concept. This may lead to heterogeneous practices of PS and ambiguous perception of PS ethics including a deleterious confusion with euthanasia.

**Abstract number:** P1-126  
**Abstract type:** Poster

## Discharge Letters - Improving the Process in a UK Hospice Setting

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**Background:** There is specific national guidance for hospital discharge letters (Royal College of Physicians 2007, UK). None currently exist for hospices, yet the same principles apply to ensure continuation of quality care in the community. Hospice discharge letters are dictated using a template, typed, signed and sent out. There are no time frame standards for this process, compared to a standard of 24 hours in hospitals.

**Objectives:**

- 1) Assess if letters follow the hospice template
- 2) Compare template to national guidance - are missing areas relevant?
- 3) Assess time for letters to be sent out.

**Methods:** The last 50 discharge letters were compared against the hospice template. Time between discharge and the letter being typed was assessed. The hospice template was compared to the RCP 'mandatory' headings.

**Main results:** 5 letters informing of transfer/death were excluded. Patient details and diagnosis were present in 100%. 44 patients (98%) had their medications listed, but 9 patients (20%) had no allergy status. Of 18 patients on steroids 4 (22%) had no steroid plan. 41 (91%) of the patients had outcomes/actions recorded but with inconsistency in presentation - 10 patients (22%) had a clear plan at the end of the letter. Patients' preferred place of care (PPC) and preferred place of death (PPD) were included in 16 (36%) and 9 (20%) of letters respectively. The mean time for letters to be typed was 1.6 days with a range of 0-6 days. Our template included 15 of the 29 RCP 'mandatory' headings. Missing items included 'relevant investigations and results' and 'medication changes'.

**Discussion:** We could improve our use of the current template, especially regarding outcomes/actions, PPC and PPD. Potential delays with dictation, typing and signing means the system needs review to ensure GPs receive information efficiently. The template also needs review to comply with national standards where relevant. A focus group is planned to discuss the results and instigate change.



**Abstract number:** P1-127

**Abstract type:** Poster

## Gold Standard Service: Audit of District Nursing Support for those Approaching the End of Life

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**Background:** Patients who may be within the last year of life (Gold Standards Framework (GSF) eligible) require close monitoring and assessment to ensure their needs, and those of their family, are met. The District Nurse (DN) is keyworker, alongside the GP, in this assessment and care (NICE 2004). Each DN team is likely to have developed their own way of addressing the needs of these vulnerable patients. There are common needs which perhaps should be addressed more consistently.

**Aim:** To undertake a baseline audit against standards based on the GSF model of care.

**Method:** A retrospective audit was undertaken of 20 sets of DN records from two DN teams against 33 standards set - stable phase: 12 standards, unstable/deteriorating phase: 8, last days/hours: 8, 4 in the immediate, and one later in, bereavement phase. The resulting intervention, the development of a DN GSF Care Plan and a Carer's Care Plan based on these same standards, was implemented before the audit was repeated.

**Results:** In the first cycle, 10 standards were met in over 80% sets of clinical records with only one standard met 100% of the time, 8 standards met in 60-80% and 18 met in 55% or less, with 4 standards never met. For an individual patient 33-77% of standards were met. Following the intervention, in the second cycle, 24 standards were met in over 80% sets of clinical records with 16 of these standards met 100% of the time, 2 standards met in 60-80% and 6 were met in 55% or less, with no standards never met. For an individual patient 61-100% of standards were met.

**Conclusion:** It is clear that a consistent model of care with agreed standards owned by DN Teams, make a significant difference to the organisation of DN support in those approaching and experiencing end of life, and the families who care for them. The Community of Practice of Band 6 DNs responsible for end of life care in the community is embarking on a baseline audit prior to implementing the same plans.

**Abstract number:** P1-128

**Abstract type:** Poster

## Low Molecular Weight Heparin (LMWH) - Prescription Audit for Prevention of Vascular Thrombo Embolism (VTE) in Inpatient Hospices

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**Background:** Venous Thromboembolism (VTE) is a recognised problem in cancer patients. The treatment involves primarily Low Molecular Weight Heparin (LMWH). We have developed Local Guidelines to reduce prescribing errors for LMWH.

**Standards:**

Patient must be weighed prior to start of LMWH and dose calculated based on weight, clinical condition, and renal function.

Should be weighed during their treatment and recorded with the date in Drug chart and clinical record.

Renal function should be obtained as soon as possible.

Dose, weight, renal function, indication and duration of treatment should be included in the discharge letter.

**Methodology:** Retrospective case notes review 2012-13. 44/52 records were available for review.

**Results:** The reasons for anticoagulation were PE:15,DVT:18,AF:2, Prophylaxis:4, CVA:2,DVT and PE:2,unable to identify:1.

7/44, started by the Hospice team. Five patients had dose reduced and seven had LMWH stopped during their admission. All the patients who had LMWH started by the Hospice team had their weight and the dose appropriate for their weight. Only 3/7 had weight recorded during the treatment. 6/7 had weight recorded in their notes and drug chart. Renal function was recorded in 38/44 patients. Discharge letter: Dose was recorded in all letters. Weight was recorded in only 2/32 (12 N/A), Indication recorded in 13/36 (N/A:8), Renal function communicated in discharge letter for 6/34 (N/A 10), Plan (Duration) for LMWH was in only 3/36 letters (N/A:8).

**Conclusion:** The audit demonstrated some evidence of good practice and also revealed areas for improvement. Those who were started on LMWH were commenced according to the guidelines. However, many areas like evidence of review of the dose, checking of weight and especially communication with the GP when the patients were discharged need significant improvement to comply with the guidelines.

**Recommendations:** Results presented in the local audit meeting. To re-audit in 1 year time.

**Abstract number:** P1-129

**Abstract type:** Poster

## Audit of Drug Chart Documentation and Usage to Re-design Drug Chart in a Hospice

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**Background:** Due to planned redesign of drug charts, we audited our drug chart usage by medical and nursing staff to identify areas in need for improvement.

**Methods:** Retrospective chart analysis. 31 from inpatients during January 2014– December 2013. All the charts were obtained from infoflex (electronic patient notes).

**Results:** Patient details were complete in 28/31 patients. Three were missing data of admission and NHS number. (90%). An allergy box was completed in 28/31 patients. (90%). Three had no signature. One was incomplete – updated by the pharmacist. Medication History box in the drug chart was used in (24/31) = 77%. A steroid box was used in six patient charts. Steroid boxes in four charts were not completed when a patient was on steroids (4/10= 40%).

A communication box was used in 23/31 charts (74%) – frequently not signed by doctors to confirm that it was acknowledged. Frequency of usage of communication box: 19 charts

once, 4 charts twice, 1 chart thrice, 1 chart six times. TTO section used in 1/3 patients. 2/3 not used. 28 – not discharged. Discretionary medication are used in 6/31 charts. (paracetamol, simple linctus, saline nebuliser, bisacodyl and movicol). Drugs omitted in 22/31 charts. Reason recorded in the last page in 14/22. (64%). Legibility of drug names: 29/31 charts (94%). Doses: 27/31(87%). Instruction box used in 27/31 (87%) charts. Medications were rewritten in case of change of dose in 25/27 (93%).

**Discussion:** This audit gave a snap shot insight of the documentation of drug charts. There are some areas in need of improvement as Recording of allergies (need to be 100%), usage of steroid box in case of steroid prescription. We also noticed that recording of reason for drug omitted, signing of communication by the doctors need to be improved.

Some areas, like the instruction box for the medications need to be increased in size and the discretionary medication. The results to be presented at audit meeting, drug chart being redesigned and further audits planned.

**Abstract number:** P1-130

**Abstract type:** Poster

## Audit of Recording of Pulse and Recording of Atrial Fibrillation in Inpatients Hospice

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**Background:** Atrial fibrillation is a common cardiac arrhythmia, with a prevalence increasing with age – from 0.5% in 50–59 year olds to almost 9% in 80–90 year olds. Potentially distressing symptoms include palpitations, chest pain, dizziness as well as worsening heart failure with breathlessness and oedema. Recognising AF is important as optimal treatment is specific to AF.

**Aim:** To determine if AF is documented in Hospice inpatients. To determine if heart rate is assessed on admission.

**Method:** Computerised patients records, initial Doctors assessment and front of drug chart (Observations taken by nursing staff are documented on front of the chart) of 60 consecutive patients with a diagnosis of cancer admitted to the inpatient unit from October 2013. Data collection proforma used. Retrospective audit.

**Results:** Mean age was 70 years. 19 patients were EoLC(31.6%) – none of which had a documented pulse rate. These patients were excluded from the results. Of the remaining 41 patients, 4 (9.7%) were documented to have AF. Twenty three (62%) of patients had pulse recorded but only 7(1.8%) had rate recorded. 32(78%) of patients had recent electrolytes documented.

**Discussion:** AF was documented in 9.7% of cancer inpatients which is consistent with the reported prevalence of AF (All patients over 75 years). Although HR was documented in over half of the patients admitted to the unit only 1.7% had documentation of rhythm. Given the lack of pulse rate documentation it is likely that in a proportion of patients the condition goes unrecognised. Unless diagnosis is thought about and symptoms of atrial fibrillation actively sought at assessment, consideration of specific treatment may not occur.

**Recommendation:** We recommend that all patients admitted (except EoLC), have pulse rate and rhythm documented on admission. During the admission, if any symptoms (SOB, palpitation, chest pains), then AF should be considered if appropriate. This should be improved also during the admission (if indicated).

**Abstract number:** P1-131

**Abstract type:** Poster

## Evaluating End of Life Care at a Regional Cancer Centre: Results of a Study Using the VOICES Questionnaire

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**Background:** End of life care provided by the regional cancer centre had not previously been formally evaluated. VOICES (Views of Informal Carers-Evaluation of Services) is a validated questionnaire completed by relatives of patients who died in different care settings.

**Aim:** Assess carers' experience of quality of end of life care provided at the regional cancer centre.

**Methods:** The VOICES authors gave consent to condense the questionnaire to 35 focussed questions. The hospital Clinical Audit Sub-committee approved the study. Questionnaires were sent to the next of kin of 33 patients who died between April 2012 and December 2013. No reminders were sent. Information on bereavement services was given.

**Results:** The response rate was 21%. 57.1% felt doctors 'always' treated their relative with respect and dignity during the last admission; 85.7% felt the same for nurses. 42.9% felt the care from doctors and nurses was 'excellent'. 14.3% felt the doctors' care was 'poor'. 42.9% thought pain was relieved 'all of the time'. 14.3% of patients had said they wanted to die in hospital. 71.4% felt their relative died in the right place. 85.7% felt they were provided with enough support at the time of death. 100% felt they were dealt with sensitively. 42.9% rated the overall care in the last three months of life as 'good', 14.3% as 'excellent' and 14.3% as 'poor'.

**Discussion:** The low response rate makes the validity of the results questionable. Actions to increase the response rate would be important in the future. There was no opportunity for relatives to give explanations for some answers which would have been useful. There are challenges and ethical issues with end of life care studies, including using relatives to assess care rather than patients.

**Conclusion:** VOICES is one potential tool for evaluating end of life care in a regional cancer centre. There are limitations, making other validated tools potentially more clinically appropriate.



**Abstract number:** P1-132  
**Abstract type:** Poster

## Using Pain and Breathlessness Symptoms as Quality Indicators: Experience of a Brazilian Palliative Care Service at a Private Hospital

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**Background:** Patient reported outcomes are useful to understand if medical interventions alleviate palliative needs and burdensome symptoms perceived as such by patients, and therefore, to be used as indicators of the quality of the care provided.

**Aim:** To describe the experience of using pain and breathlessness symptoms scores as quality indicators.

**Methods:** Prospective longitudinal study. Pain and breathlessness were assessed using the Palliative Care Outcome Scale-Symptoms (POS-S) at admission (D0) and at day 3 (D1). We aimed to improve symptoms severity POS-S scores for at least 75% of patients. We used Wilcoxon signed-rank test to compare POS-S scores before and after medical intervention. **Results:** 414 patients were followed from January 2013 to July 2014. Mean age was 76 (±16) years, 213 (51%) were female and 362 (87%) were white. Malignancy was the main diagnosis in 233 (56%) patients, dementia in 51 (12%), organ failure in 44 (11%), frailty in 28 (7%), stroke in 28 (7%) and other diagnosis in 28 (7%). Pain was present at admission in 161 (39%) cases and most of them (67%) were suffering from moderate to severe pain (scores of 4 or 3 or 2). Breathlessness was present at admission in 162 (39%) and most of these patients (62%) were suffering from breathlessness, scored as moderate to severe. Only 118/161 (73%) and 111/162 (69%) of patients with pain and breathlessness, respectively, completed POS-S at D0 and D1. Improvement of symptom scores occurred in 94 (82%) and 82 (75%) patients for pain and breathlessness, respectively.

**Conclusion / lessons learned:** By recording symptom severity at admission and by day three (after medical intervention) the palliative care team was assured that their intervention improved symptom control for most patients and was assured of the quality of their care in treating those symptoms.

**Abstract number:** P1-133  
**Abstract type:** Poster

## Unplanned Palliation – Auditing the Effect of Abrupt Removal of the UK Standard Liverpool Care Pathway (LCP) on the Quality of Documented Plans for Patients Having Active Treatment Withdrawn

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The LCP was abruptly removed from use as hospital policy reacted to official recommendation of its withdrawal. This audit aimed to determine the subsequent effect on the quality of documented plans for palliative patients (round 1), and re-audit once planned hospital specific guidance emerged (round 2).

Over three months, deaths of all non-ventilated patients with a decision to withdraw active treatment were included. Notes and drug charts were checked to determine if each LCP category (Table 1) had either: a documented plan, a relevant prescribing action evident (continued or crossed off therapy) with no documentation, or 'no evidence' of any management.

**Results:** There were 9 deaths in round 1 and 11 in round 2 that met criteria.

	Analgesia		Agitation		Anti-secretories		Antiemetics	
Round	1	2	1	2	1	2	1	2
Documented plan	22%	64%	0%	45%	11%	18%	11%	18%
Prescribing action	78%	36%	78%	45%	11%	27%	33%	64%
No evidence	0%	0%	22%	9%	78%	55%	56%	18%

	Dyspnoea		Antibiotics		Nutrition		Hydration	
Round	1	2	1	2	1	2	1	2
Documented plan	22%	55%	0%	27%	11%	27%	0%	27%
Prescribing action	22%	0%	78%	64%	44%	0%	89%	27%
No evidence	56%	45%	22%	9%	44%	73%	11%	45%

[Table 1 LCP categories]

**Discussion:** Round 1 documentation for each category was minimal. This improved across all categories by round 2, though this was most marked for analgesia, agitation, dyspnoea and antibiotic plans. There was also a reduction in the 'no evidence' scenario for near all categories, partly from improved documentation but also increased prescribing activity. The exceptions to this were nutrition and hydration, which had an increase in the proportion of 'no evidence', though these are often the source of most concern for patients and families. Their non-pharmacological nature perhaps explains their oversight. Given how broad one must be in considering all holistic needs of the dying patient, we conclude clinician's do benefit from guidance to plan palliative care.

**Abstract number:** P1-134  
**Abstract type:** Poster

## Hospital Discharge Advance Care Plans in the Netherlands; Evaluation of a Pilot Study

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Advance care planning improves palliative care for patients and their families. The Provincial

Palliative Team Groningen, founded in 2013, aims to provide an advance care plan (ACP) for all patients with a life expectancy of less than three months. In this pilot study, palliative patients in three Dutch hospitals were given an ACP upon discharge. This document, which remained with the patient throughout, covered four themes: end-of-life decisions, medication, a tailored plan regarding policy towards anticipated problems and possible interventions, and an overview of current problems in the four palliative dimensions.

Ninety-eight plans were filled out from April 2013 to September 2014. Policy regarding readmission and CPR was recorded in 89% of ACPs; 75% stated whether euthanasia or palliative sedation had been discussed. Medication was often recorded in a separate document. The average number of anticipated problems was 3.2; a solution was provided in 90% of cases, 50% of which followed national guidelines. Expected problems were mostly physical in nature. Of the current problems, physical problems were reported in 81%, socio-economic ones in 16%, psychological or spiritual ones in 43% and care-related problems in 68% of the ACPs.

The high documentation rate of advance directives with respect to readmission and cardiopulmonary resuscitation on ACPs is a favourable outcome, although no baseline is known. In the ACPs, fewer problems were anticipated on average than expected based on previous studies. This may be due to underrecognition. National guidelines were not followed for palliative treatment suggestions in half the cases, possibly due to a lack of expertise. In the four problem quadrants, psycho-spiritual and socio-economic problems were underreported, perhaps because they are not traditional medical domains. We therefore conclude that education regarding palliative guidelines, ACPs and their role in optimal palliative care is required in hospitals.

**Abstract number:** P1-135  
**Abstract type:** Poster

## Developing and Implementing National Evidence Based Clinical Guidelines in Palliative Care

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**Aim:** Developing and implementing national evidence based clinical guidelines in palliative care.

**Method:** The Danish Multidisciplinary Cancer Group of Palliation (DMCG-PAL) aims to develop national evidence based clinical guidelines since 2010. Participants are from hospices, palliative departments and teams all over Denmark. The groups consists of participants with both clinical and academics skills. Participants receive education in preparation of focused questions, literature search and analysis, assessment of the literature and evidence-determination. Employees with academic skills make the research and analysis of the literature, and decide together with employees with clinical skills, which literature is useful for recommendations.

A coordinator is selected to lead and sustain the process. Every palliative department and hospice providing staff and pay for transportation, costs and catering.

**Results:** 59 nurses, 17 physicians, 2 psychologist, 6 physiotherapists, 1 social worker, 1 music therapist and 2 chaplains cooperate on developing of 22 clinical guidelines within 12 palliative symptoms (dyspnoea, delirium, pain, cognitive disturbance, lymphedema, death rattle, obstipation, fatigue, fluid therapy, young carers and palliative sedation). Eight guidelines have been accepted by The Danish Clearinghouse for Guidelines. Tree guidelines are published as systematic literature searched area. Four guidelines have been sent to Clearinghouse for judgement in autumn of 2014, and seven guidelines will be ready for judgement during 2015.

**Conclusion:** Throughout the four years DMCG-PAL has been established, it has proved that it is possible to develop national, multidisciplinary evidence-based clinical guidelines. The presence of managerial, academic and clinical skills is a prerequisite to develop clinical guidelines. Participants gain skills in systematic methodology and are responsible for implementing the guideline in their own department.

**Abstract number:** P1-136  
**Abstract type:** Poster

## Audit of Intravenous Infusions of Bisphosphonates Carried out in the Community over a Twelve Month Period

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**Background:** Intravenous bisphosphonates are routinely administered in hospital. This community service aims to provide interventions at home.

**Method:** The electronic notes of all patients who had an intravenous infusion of a bisphosphonate in 2012 were reviewed. Clinical and demographic data extracted included diagnosis, assessment prior to infusions, number of infusions given, documentation of discussions about side effects and risks of treatment, and ongoing treatment plan.

**Results:** Over this 12 month period 36 infusions were administered, to 10 patient. The number of treatments ranged between 1 and 9.

In 7 cases zoledronic acid was administered and in 3 cases pamidronate.

The infusions were either initiated by the patient's oncologist in hospital and then were transfer over to the care of the MMT for future treatments, or in 2 cases were started by the MMT after discussion with their oncologist.

There were 4 male, 3 prostate cancer, 1 renal cell carcinoma and 6 female, 5 breast cancer and 1 colon cancer, all patients had bone metastases. For 5 of the patient bisphosphonate infusions were administered to help in the management of their pain. None of these patient received bisphosphonates to treat hypercalcaemia. Their ages ranged from 60-85 y.o (73).

The infusion was prescribed in accordance with recommend treatment guidelines.

In only 2 cases was there documentation that the possible side effects and risks of treatment had been discussed with the patient.

**Discussion and conclusion:** Patients expressed their appreciation of the service as it avoided attendance at hospital. The infusions were carried in the majority of cases in their own homes.

Four patients infusions given at the Pearson Unit when the MMT is based.

Following this audit it has been recommended improved documentation of side effects and risks of treatment. That nurses ask about side effect particularly dental issues, and if indicated examine the patients mouths.

**Abstract number:** P1-137

**Abstract type:** Poster

## Initiating Opioids in Patients with Advanced Disease: How Well Are We Doing?

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**Background:** Pain is common and prevalent in patients with advanced, disease. Advice on prescribing strong opioids has previously been varied. In the UK, NICE published opioid prescribing guidance in palliative care. It is not known how well prescribers are adhering to these guidelines.

**Aims:** To assess how compliant medical and non-medical prescribers in an NHS trust are with standards on opioid initiation and providing patient information

### Methods:

1) Retrospective analysis of inpatient ward initiation of opioids from 2 acute hospitals and 2) Prospective analysis of community and outpatient opioid initiation was undertaken at a joint UK acute and community trust.

The retrospective arm involved completion of proformas for inpatients started on strong opioids who were either referred to the palliative care teams or known to have been started on opioids by other teams. Pharmacy lists of opioid prescriptions in hospital were also made available. Prospective arm: Prescribers completed proformas at time of initiation of strong opioids. Data collected included demographics, opioid prescription information, and information given to patients. Summary statistics used to describe data.

**Results:** 110 patients were included (92% retrospective, 8% prospective). 75% of patients had cancer. Less than half of patients were started on oral morphine first line. 61% of patients were started on a daily dose of 20-30mg of oral morphine. Laxatives were co-prescribed in 60%. Oral morphine was prescribed as maintenance therapy in 35% of patients. In only one third of cases were patients asked about concerns of treatment. Written information was given in only 6% of patients. Patients didn't have advice about constipation or nausea in 60% of cases.

**Conclusions:** There were areas that did not meet NICE guidance in terms of opioid prescribing and provision of written information. Future strategies include specific prescriber education and development of comprehensive written information on opioids.

**Abstract number:** P1-138

**Abstract type:** Poster

## Responding to Demand and Finding Ways to Work Smarter. An Audit into Increased Numbers of Referrals to a Hospital Palliative Care Team

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**Aims:** A significant increase in the number of inpatient referrals to the Palliative Care team at the Royal Free Hospital, London was noted in the first 3 months of 2014. A retrospective review of referrals received was undertaken to investigate the possible causes of this.

**Design:** All referrals taken between the 1st January and the 31st March 2014 were identified using the palliative care database iCare. Data was recorded on the number of referrals taken each day, level of urgency, teams making referrals, aim of referral, appropriateness of referral and patient outcomes.

**Results:** 251 sets of notes were reviewed; 2 sets of notes were missing. The number of referrals each day ranged from one to nine and there were significantly more referrals on Mondays and Thursdays. 139 referrals (55.4%) were non-urgent and 81 (32.2%) were prioritised as urgent. Over half (53.2%) of all referrals were made by the Oncology and Geriatrics teams. 69 referrals (27.5%) were from medical specialties. Patients were mainly referred for symptom control (62%). Only 19 referrals (7.6%) were considered inappropriate. Patients remained under the palliative care team for an average of 9.5 days (range 1-55). 119 patients (47.4%) were discharged to home, hospice or nursing home and 86 patients (34.2%) died.

**Conclusions:** The increase in total number and urgency of referrals in combination with an increased length of time of required palliative care input may reflect an increasingly complex patient case-load with multiple co-morbidities. The majority of referrals were for symptom control and an increase in non-malignant referrals was noted. The significantly increased number of referrals on certain days seems related to the timing of referring Consultants' ward rounds. As a result of this work, we have proposed cross-specialty ward rounds and further education for hospital multi-disciplinary teams regarding the role of the Palliative Care team.

**Abstract number:** P1-139

**Abstract type:** Poster

## Early Screening for Palliative Care Needs in the ICU: A Multihospital Replication

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**Background:** An initial study in 4 hospital ICUs in Detroit demonstrated good predictive value of a palliative care (PC) screen for hospital and ICU LOS, mortality, and hospice referral.<sup>1</sup>BMJ Supportive and Palliative Care—4/2014.

**Aims:** The goal of this study was to replicate these results in an independent sample.

**Methods:** The seven item screen was applied to MICU patients upon admission in 3 different ICUs in a Mid West and Southern City in the US over a 16 week period. Outcomes included percent of patients screened for and received a PC consult, and association of screen with LOS, inpatient mortality, and hospice referrals. Individual screen factors were regressed against a composite variable of inpatient mortality or hospice referral.

**Results:** A total of 497 patients were screened, and had a mean age of 63.0 years [SD:16.4]; 206 patients were positive (67.0 years:SD 14.8) and 291 were negative (60.1 years:SD 16.9, p<0.001). Positive vs. negative screened patients were not different by race or gender. One third (35.3%) were screened positive, and 33.6% of positive screens received a PC consult compared to only 3.4% who screened negative. Positive screens were associated with statistically significantly increased hospital and ICU LOS, and inpatient hospital mortality and hospice discharge. Admission for a Skilled Nursing Facility and Readmission to

the ICU were associated with hospital LOS; metastatic cancer, post arrest with neurological compromise, and perceived need for palliative care were associated with the composite of death or hospice discharge.

**Conclusion:** Study of the ICU screening instrument in an independent population again found 5 factors positive associated with patient outcomes, but again demonstrated no predictive value of end stage dementia or intracranial hemorrhage. PC screening in the ICU with 5 validated predictors is recommended for the detection of patients for PC who will experience a high percentage of adverse outcomes.

**Abstract number:** P1-140

**Abstract type:** Poster

## Multi-hospital Replication of a ICU-screen for Palliative Care

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**Background:** An initial published study of four hospital ICUs in Detroit demonstrated that a seven-item palliative care (PC) screen had good predictive value for hospital and ICU LOS, mortality, and hospice referral. Our goal was to replicate these results in an independent sample.

**Aims:** To assess the relationship between each of the individual screening factors and the outcomes.

**Methods:** The same screen was applied to MICU patients upon admission in three different ICUs in two US-cities over a 16-week period. Outcomes included percent patients screened, consulted by PC, and association with LOS, inpatient mortality, and hospice referrals. Individual factors were regressed against a composite variable of inpatient mortality or hospice referral.

**Results:** A total of 497 patients were screened. Mean age was 63.0 years [SD:16.4]. Positive vs. negative screened patients were different by age (206 positive patients were 67.0 years [SD 14.8] and 291 negative were 60.1 years [SD 16.9, p<0.001] but not by race or gender. Of those 206 who screened positive, 33.6% received a PC consult compared to only 3.4% who screened negative. Positive screens were associated with statistically significant increases in hospital and ICU LOS, and inpatient hospital mortality and hospice discharge. The items 'admit from Skilled Nursing Facility' and 'Readmission to ICU' were associated with increased hospital LOS; metastatic cancer, and post arrest with neurological compromise. Perceived need for palliative care was associated with death or hospice discharge.

**Conclusion:** Study of the ICU screening instrument in an independent population found the same five factors were positively associated with patient outcomes, but again demonstrated no predictive value of end-stage dementia or intracranial hemorrhage. PC screening in the ICU with the five validated predictors is recommended.

## Basic and translational research

**Abstract number:** P1-141

Abstract withdrawn

**Abstract number:** P1-142

**Abstract type:** Poster

## Evaluation of Detachment and Clinical Usability of Transdermal Fentanyl Patches in Healthy Volunteers

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**Aims:** A dose of transdermal fentanyl patch is proportional to its application site area; therefore, the absorption of fentanyl may lower if the patch detaches, and it would lead to insufficient analgesia.

**Methods:** Sixteen healthy volunteers were enrolled in a study where we investigated appropriate application sites and clinical usability of the three transdermal fentanyl patches available in Japan. Three placebos were administered using a crossover study design: fentanyl 1-day (Fen), 3-days (Dur), and the generic form of Dur (HMT). These placebos were applied to eleven different sites (both sides of upper arm, abdomen, back, thigh, chest and middle of chest). We determined a patch detachment area and incidence of itching sensation considered to be induced by patch application every 24 hours, and evaluated differences between each application site by using Wilcoxon signed-rank test.

**Results:** With regards to detachment area, the abdomen and upper arms in Fen, abdomen and chest in Dur, and chest in HMT, respectively, showed significant patch detachment compared to other sites (p < 0.005). Although the results obtained yielded no significant difference of a level of itching among the regions applied when administering Fen, we found statistically-significant increase in itching on the chest and back with the administration of Dur and on the abdomen in HMT compared to other sites, respectively (p < 0.05).

**Conclusion:** It is considered, in Dur and HMT, thigh and upper arms are suitable as an application site because there was less incidence of patch detachment and itching sensation compared to chest and back. Fen, reapplied every 24 hours, has showed less detachment and itching sensation than Dur and HMT, reapplied every 72 hours, which would indicate Fen specifically improves the quality of life in patients with cancer pain rather than Dur and HMT.

Abstract number: P1-143  
Abstract type: Poster

### The Biology of Dying: A Systematic Review

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**Background:** Diagnosing when someone is in the last hours or days of their life is an ongoing difficulty for clinicians. There is often significant clinical uncertainty and modern medical science is poor at predicting how, when patients will die. It is important to recognise this change, however, to guide appropriate medical management and patient care.

**Aim:** To review the literature to assess the knowledge of the biology of dying - excepting sudden death.

**Method:** A systematic review of the biology of dying was performed using PRISMA guidelines. 2322 articles on MEDLINE and 3016 articles from EMBASE were identified. From 5338 titles, 117 abstracts were selected. Titles and abstracts were examined independently for relevance by Coyle and McDonald, with 43 papers selected for review.

**Results:** There are no published studies that specifically investigate biochemical changes during dying. The evidence which does exist has been gained are from postmortem studies or from patients in studies who have incidentally died, where biological assessments have been undertaken. Hence, there is some knowledge about biochemical changes causing cachexia and anorexia, and limited knowledge about terminal dehydration, terminal secretions, dyspnoea and agitation. Evidence from these studies seem to suggest the existence of a common dying process and highlight various potential biomarkers, such as Interleukin-2 or Interleukin-6.

**Conclusion:** There are no specific studies investigating biochemical changes during the dying process. Research into the biological changes at the end of life could develop a greater understanding of the dying process and have the potential to significantly impact the care future dying patients receive.

Abstract number: P1-144  
Abstract type: Poster

### Health Professionals' Experiences of Transferring Critically Ill Patients Home to Die. A Comparison of Adult and Paediatric Intensive Care Staff

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**Background:** A significant proportion of hospital deaths occur in intensive care units. In circumstances of treatment withdrawal, death can be planned, raising issues surrounding preferred place of death. The aim of this research was to determine the experiences of UK health care professionals (HCPs) towards transferring critically ill patients home to die and more specifically to compare experiences in paediatric as opposed to adult units.

**Methods:** An online survey developed to investigate experience, views and barriers to transfer home to die, was sent to HCPs from 409 UK adult intensive care units (ICU). An adapted version was sent to 900 UK neonatal and paediatric ICU HCPs. Comparative analyses of the two datasets were carried out.

**Results:** A total of 180 HCPs from adult ICUs and 191 from NICU/PICUs completed the surveys. HCPs from NICU/PICU were significantly more likely to report having experience of transfer home to die than adult ICU HCPs (70% versus 36% respectively;  $\chi^2=44.570$ ,  $p=0.000$ ), and significantly more likely to discuss transfer home (75% versus 16%;  $\chi^2=53.347$ ,  $p=0.000$ ). All HCPs reported positive views (measured by 17 statements), while NICU/PICU HCPs reported more agreement in being able to organise a transfer home ( $U=9918.500$ ,  $p=0.000$ ). NICU/PICU HCPs were more likely to disagree that transferring home is a waste of health care resources ( $U=11717.000$ ,  $p=0.000$ ), compared to adult ICU HCPs. For both adult and NICU/PICUs, the most frequently reported barriers were a lack of community access and concern that patients' relatives were unlikely to cope with the transfer or death at home.

**Discussion:** These surveys are the first to explore the experiences of UK HCPs about transferring critically ill patients home to die and explore differences between adults and paediatric ICUs. While perceived barriers were similar in both settings, results suggest that HCPs in NICU/PICU have more experience of transfer than adult ICU HCPs, which could affect HCP views.

## Bereavement

Abstract number: P1-145  
Abstract type: Poster

### Bereavement Outcomes of Family Caregivers: Do Spousal and Adult Child Caregivers Experience Grief Differently, and what Factors Influence this?

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**Background:** Family caregivers (FCs) are at higher risk of complicated grief (CG) than the general bereaved population. The understanding of risk factors (RFs) for CG in FCs is incomplete, in particular, whether some RFs are particularly relevant to certain FCs.

**Objectives:** Describe and compare bereavement outcomes of spousal and adult-child FCs; and determine the relative importance of certain RFs for CG for different FCs.

**Methods:** Secondary analysis of data from the Qualycare study, which examined care provided to people in the last stages of life. Data analysis: independent samples t-tests, correlation,  $\chi^2$  tests, multiple regression analysis.

**Results:** 246 adult-child and 238 spousal FCs were included. Spousal FCs experienced higher grief intensity (GI) and more prolonged grief ( $p < 0.001$ ), and sought formal support more frequently than adult-child FCs ( $p < 0.001$ ). Female gender of FC and younger patient age predicted 24.2% of variance in GI for adult-child FCs; 8.3% for spousal FCs. Patients with adult-child FCs were significantly more likely to die in a nursing or residential home ( $p < 0.001$ ). This was associated with lower GI for adult-child but not spousal FCs. Intensity of caregiving was similar in both FC groups, but predicted 11.6% of variance in GI for adult-child FCs, compared to 0.5% of variance for spousal FCs. Higher patient severity of psychological and physical symptoms, and FC anxiety, were associated with higher GI ( $p < 0.001$ ).

**Conclusions:** Effective risk assessment for CG allows targeting of interventions shown to improve outcomes. Results showed that female FCs caring for younger patients, and spouses, are at risk of CG, and should be targeted for secondary intervention. Intensity of caregiving was an important risk factor for adult-child FCs, highlighting role strain, and the importance of the 'relief model' of bereavement for this group. Clinical recommendations, methodological challenges, and implications for future research are discussed.

Abstract number: P1-146  
Abstract type: Poster

### Experience of Mourning Counselling in a Palliative Care Department

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**Background:** It seems consensual that between normal bereavement and bereavement related psychiatric disorders there is a wide range of complicated mourning reactions. Between 10-17% of those who seek psychiatric support show signs of complicated mourning.

**Aims:** To characterise the carers attending a mourning counselling in a Palliative Care Department in a University Hospital, selected by the Complicated Mourning Screening Protocol (CMSP) developed by the team.

**Methods:** To analyse clinical records of carers attending the Mourning Counselling between november 2013 and august 2014 using the Worden Theoretical Model (WTM). Risk factors and protective factors of complicated mourning were evaluated by the Barreto, Yi and Soler model (2008).

**Results:** Twenty one carers were evaluated, 14 (67%) selected by the CMSP and 7 (33%) seeking help spontaneously, of which 6 were discharged by not having emotional distress bereavement. Three carers (2 widows and 1 daughter) presented criteria for complicated mourning. By this abstract deadline, 10 carers (48%) were discharged of the mourning consult being in the IV Worden Task (median follow up 53 days, 2.5 appointments). The 11 carers still accompanied (median follow up 90 days) were all in the II Worden Task at first appointment and the most frequent risk factors were: emotional bond intensity (100%), affective dependence (100%) and rapid disease progression (55%). As protective factors we identified the sense of utility care (91%), self-recovery confidence (73%), selfcare capacity (73%) was identified and religious beliefs (63%). Most frequent complaints were sadness and nostalgia.

**Conclusion:** Our results concerning the complicated mourning are similar to those reported in literature and in the 10 months follow-up about 48% of the carers were discharged for not having emotional distress lost related. At first appointment the majority of carers (60%) were in the II Worden Task.



**Abstract number:** P1-147  
**Abstract type:** Poster

## Identifying Risk Factors and Coping Style of Complicated Bereavement

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**Background:** The well being of family and others close to a dying patient with cancer is part of the medical team's responsibility in terminal illness. Health providers have a continuous responsibility to assist the bereaved and to recognise the individuals at risk of developing abnormal grief reactions to the loss of the loved one.

**Aims:** The assessment of the vulnerability and coping factors will assist in identifying those family at risk of adverse effects of bereavement and will allow early therapeutic interventions.

**Methods:** The primary caregivers of cancer patients with end-stage disease who presented for the first time in our department were screened, shortly after arrival, using Bereavement Risk Assessment Tool. The questionnaire was conducted by nurses, using structured interviews and personal observations. The risk and protective factors were identified and compared with that in the literature.

**Results:** Of the 252 patients admitted to our department in a period of 2 weeks, 83 patients presented for the first time to palliative care unit and 70 caregivers agreed to respond to the interview. At 22.85% (16) caregivers was identified at least one risk factor positive in more than four groups of factors: comorbidities, concurrent stressors, circumstances around the death, lack of supports, relationships. 37.14% (26) caregivers reported self-expressed concerns regarding own coping or abuse/dependency in relationship with the patient. 42.85% (30) caregivers reported lack of social support.

More than three protective factors were identified in 37.14% caregivers. 20% (14) caregivers could be considered at serious risk of complicated grief.

**Conclusion / Discussion:** The diagnosis of cancer, by its specific prognosis and progression, may be considered an adaptive factor to bereavement. Most caregivers find the internalised belief in own ability to cope effectively with the death of their loved one.

**Abstract number:** P1-148  
**Abstract type:** Poster

## 'Rising from the Mist': Systematic Review of Grief Reactions in Family Caregivers of Advanced Cancer Patients

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**Background:** The question remains whether we know enough about family carer's grief in cancer end of life care and how this affects their preparedness for caregiving, care delivered and how their well-being is impacted.

**Aim:** We systematically reviewed the literature on anticipatory and post-death grief in families with advanced cancer patients guided by the questions: what are the prevalence, characteristics, predictors, and experience of grief reactions?

**Method:** Searches were conducted May-September 2014. Sources included data bases (PsycINFO, MEDLINE, CINAHL, EMBASE), hand searches of journals' contents and reference lists, existing systematic reviews and conference abstracts.

The studies were included if describing grief in family carers of advanced cancer patients. We excluded studies that were non-grief or non-cancer specific. Qualitative and quantitative studies were assessed. Two reviewers assessed abstracts and methodological quality.

Progression of research over time, findings on subjective experience, prevalence, associations and predictors of grief are presented.

**Results:** We found 33 studies, 4 qualitative. More than half of studies presented are part of a larger study, with grief not being one of the primary outcomes. Carers experience anticipatory and post-death grief as multiple losses for themselves and the person with cancer. Core subjective features are ambiguity, dual roles and losing balance. A multifaceted profile of risk factors was found. Prevalence rates were up to 40%. Links between anticipatory and post-death grief seem to be non-consistent.

**Conclusion:** Grief in caregivers of cancer patients can be expected in anticipation of imminent death. Secondary stressors in predicting grief reaction post-death are important. The continuum of grief might be more complex phenomena than identified in present research. There is a lack of longitudinal and prospective studies needed to embrace the grief's processual nature.

**Abstract number:** P1-149  
**Abstract type:** Poster

## Linguistics and the Burden of 'Guilt' in Bereaved Relatives

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**Background:** At a conference on 'Ethics of Choice: Implications of a National Choice Offer in End of Life Care in End of Life Care'. Bereaved carers described their care experiences in the context of trying to fulfil a dying patient's choices. They described how they were left with feelings of 'guilt'. When explored this feeling of 'guilt' focussed on could they have done better. As the debate opened to include conference participants the word 'guilt' became a recurrent theme, especially in relation to relatives feelings if, for example, their loved one's preferred place of death could not be achieved.

**Aim:** To explore the linguistics of 'guilt' in bereavement considering implications for the psychological and spiritual wellbeing of bereaved relatives and for the language and policy of choice.

**Methods:** Review of the literature on guilt and bereavement. A linguistics based analysis of synonyms and their meanings and use. Exploration of 'guilt' with a Public Health Practitioner, Ethicist and Theologian. Exploration of meanings of 'guilt' in a bereaved relatives' focus group.

**Results:** Feelings of 'guilt' are a recognised feature of bereavement. The word is widely used in common language representing a range of synonyms: regret, shame, contrition, fault, culpability, doubt. A key theme was the high expectations created by medical professionals, albeit with the best intentions, about a good death, particularly preferred place of death for the loved one.

**Conclusions:** Guilt is a term commonly used by bereaved relatives. There appears to be a 'taught/professionalised' or 'learned' element in common parlance to sum up a range of concerns. This has important implications for the psychological and spiritual wellbeing of bereaved relatives as 'guilt' implies fault for a bad action. Health professionals should communicate realistic expectations around caring of the dying with more emphasis on unpredictability of dying and explore the bereaved's interpretation of guilt in giving advice.

**Abstract number:** P1-150  
**Abstract type:** Poster

## Creating Memories for Children and Young Adults within the Acute Hospital Trust

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**Background:** BHRUT hospitals charity Treasured Memories Appeal was set up in 2006 following an audit that highlighted that there was an unmet need for patients that had children and wanted to create memories.

**Aim:** To provide ongoing support to a bereaved child or young person whose parent has a life limiting illness.

**Method:** The appeal team researched the available resources and embarked on fund raising events to gain finances to purchase the aids. These consisted of a range of aids from Memory Boxes to purchasing presents for future life events. The resources have grown since the set up and in conjunction with the expertise of the health care professionals have helped to facilitate conversations and activities.

**Results:** In the last two years since the project gained momentum, staff have become confident in facilitating these types of conversations. 104 memory boxes have been created, 2 computers have been purchased with wifi access in order for patients to link up with events that they are not able to attend. The following have been recorded by patients and their children, 'Just to see their faces as they opened their presents was wonderful. You allowed my children to have a great Christmas to remember me by'. 'I was able to take photo's of Mummy on our special days out, which helped me to remember her'. An 8 year old boy was able to cut a piece of his mum's hair to place in his memory box and named his new teddy bear the same nickname his mother had called him.

**Conclusion:** Treasured Memories are now at the forefront of the team and have enriched the knowledge in facilitating these types of conversations. The feedback from patients and families has been positive, which highlighted the difference it makes to patients and families in creating memories.

**Abstract number:** P1-151  
**Abstract type:** Poster

## Symptoms and Suffering Perception at the End of Life of Cancer Children and the Impacts on the Caregivers

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**Background and aims:** Little is known about the symptoms and suffering at the end of life in children with cancer. Facing this, we assessed the perception that parents have of the symptoms and suffering that the children underwent at the end of life, and the presence of mood disorders and grief reactions in the parents and their correlations.

**Methods:** In 2012, 250 families that had lost a child between the years of 2000 and 2010, in a specialised, public hospital in Brazil, were contacted. A survey was carried out through self-applied questionnaires sent by mail (Hospitalar Anxiety Depression Scale - HADS and Texas Revised Inventory of Grief - TRIG).

**Results:** 60 caregivers with time of mourning ranging between 14 and 80 months reported, on average, 12 symptoms that affected the well-being of their children on their last week of life. The presence of a symptom during the last week of life of the child showed no association with complicated grief.

These parents present with high levels of anxiety and depression (74.0% and 81.0% respectively), as well as complicated grief (38.0% absent/ low grief, 12.0% delayed grief and 34.0% prolonged grief).

When the variables related to present grief were analysed, there was strong positive correlation with past grief, showing anxiety and depression; and negative correlation with palliative care time. As predictor factors in the multiple regression analysis, past grief and depression were evident.

**Conclusion:** Parents related great suffering of their children in the end of life. There was strong positive correlation between present and past grief with anxiety and depression, and with the burden of symptoms referred by doctors, and negative correlation with palliative care time.



## Communication

**Abstract number:** P1-152  
**Abstract type:** Poster

### Research Results Transfer of the Atlas of Palliative Care Projects

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**Background:** As Palliative care (PC) research develops and matures, an increasing emphasis is being placed on knowledge transfer and impact.  
**Aim:** To describe the process of results transfer from three research studies carried out in the University of Navarra: Atlas of Palliative Care in Europe (2013), Supplement on Specialisation in Palliative Medicine for Physicians in Europe (2014) and Latin American Atlas of Palliative Care (2014).  
**Method:** Descriptive study involving a follow-up of analytical data structured on three axes: dissemination strategy, concrete actions, and results. As to 9th October 2014  
**Results:**  
a) Dissemination strategy: presentations at congresses, press releases, social media announcements, echoes and hosting in related institutional websites, development of free electronic app and mailing;  
b) Concrete actions: delivery of printed copies amongst the congresses attendants, press notes sent to press agencies, uploading of documents to online repositories, hosting in Android and Apple platforms and mailing to PC national associations, scientific journals and Ministries of Health;  
c) 3269 delivered copies at congresses, over 100 press news, over 2000 downloads and 3400 views, and downloaded over 400 times from the Android and Apple applications.  
Other results are the 26 citations of the European Atlas, 8 times for the Latin American in google scholar, three published reviews, related articles and five citations in oral presentation of the EAPC world congress of Prague.  
**Conclusion:** The multiple dissemination strategy resulted in great diffusion. Although real impact is difficult to measure, potential impact in form of citations and use has been documented and gives encouragement to further efforts.

**Abstract number:** P1-153  
**Abstract withdrawn**

**Abstract number:** P1-154  
**Abstract type:** Poster

### Diagnosis Disclosure: A Survey of the Attitude of Family Physicians

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**Background:** The disclosure of the diagnosis of a life-threatening disease is a matter which varies geographically depending on various aspects being the cultural the most important one.  
**Aim:** To study the attitudes of general practitioners concerning this important aspect of care.  
**Methods:** A questionnaire specifically developed for this survey was sent to about 10% of the general practitioners in the Northern region of Portugal.  
**Results:** The study included 159 doctors with a median age of 43 years (26 to 64) and 108 (68%) of them were females. 107 (67%) usually disclosed the diagnosis with a significant difference between genders: 78% of men vs. 62% of women (p=0.04). 102 (64%) proactively questioned patients about their wish to know the diagnosis. 61 (38%) would use the term cancer often but only 11 (7%) used that word always. In this case, dividing by the median age, we verified that the younger doctors used the term cancer more frequently than the older doctors: 39 (49%) vs. 22 (28%) (p=0.022). 92 (58%) disclosed the diagnosis to families often, with the elder doctors doing it more frequently: 53 (67%) vs. 39 (49%) p=0.022. For 85 (54%) the disclosure is psychologically deleterious, and for 117 (74%) the disclosure has a detrimental effect on patients' hope. On the other hand, 90 (57%) think that the disclosure gives patients control of the situation often to always and more 57 (36%) answered sometimes. In the experience of 37 (23%) doctors, families ask them frequently not to disclose the diagnosis to the patient and more 84 (53%) answered that families sometimes do that.  
**Conclusion:** General practitioners disclose the diagnosis of a chronic life-threatening disease often, especially at patients' request. It is also frequent to disclose the diagnosis to family members mainly when patients are cognitively impaired. They think that the disclosure may affect hope but may also give patients more control of the situation.

**Abstract number:** P1-155  
**Abstract type:** Poster

### Family Physicians Opinions and Difficulties in Breaking Bad News

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**Background:** The process of communicating with patients with an advanced life-threatening disease concerning breaking bad news is a matter which varies geographically depending on various aspects being the most important the cultural one.  
**Aim:** To study the opinions and difficulties of general practitioners concerning this important aspect of care.  
**Methods:** A questionnaire specifically developed for this survey was sent to about 10% of the general practitioners in the Northern region of Portugal.  
**Results:** 135 (85%) doctors consider that breaking bad news is a difficult task. Many doctors think that diagnosis and prognosis disclosure may be psychologically deleterious and may have a detrimental effect on patients' hope. On the other hand, the disclosure gives patients control of the situation. Only 64 (40%) doctors feel they are prepared to do it, but they consider their colleagues less prepared than themselves, as only 38 (24%) say that those are prepared to carry out this duty. 124 (78%) physicians feel they need training in breaking bad news, but only 56 (35%) actually have attended training actions. However, only 42 (26%) doctors think that those training actions had a positive influence on their practice. When questioned about what they would want if they had a life threatening disease, such as cancer: 144 (93%) answered they want to know the diagnosis, 10 (6%) had no opinion and only 1 answered she did not want to know it; about the prognosis, 129 (83%) would want to know it, 11 (7%) would not and 15 (10%) had no opinion.  
**Conclusion:** To break bad news is still a difficult task for family physicians. Their attitude on this duty is different from what they would wish if they had an advanced life threatening disease. Most recognise they need training, but only a minority has attended training actions. Those actions seem to be largely ineffective, an aspect which should be urgently corrected.

**Abstract number:** P1-156  
**Abstract type:** Poster

### The Crucial Conversations: Communicating is a Skill that Can Be Learned and Trained

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**Background:** The need for education and training in communication skills for doctors are well known. Scientific literature, clinical experience and family stories and testimonies address complaints on respectful communication and risk for burn-out doctors.  
**Aims:** To develop and establish a communication skills training course for doctors treating patients with life-threatening diseases.  
**Method:** The course was developed by a group with medical, pedagogical and psychotherapeutic competence and two actors. Courses were evaluated using a specific questionnaire and by reflection by course leaders.  
**Results:** The course is a practice based 2-day course for 12-14 participants focused on specific situations: getting a good start, talking about serious news, transition to end-life care and talking about dying. Most time was scheduled to training with actors in small groups under supervision of an experienced and trained doctor and/or supervisor. Since 2011 eleven 2-day courses were given for > 100 doctors and a number of shorter courses based on the course concept. Evaluations showed clearly that training and supervision got the highest scores (>4 on a 0-5 scale). Participants' feedback indicated that theory, and especially, research overviews were not requested. The need for case related training, feedback and reflection with colleagues were given highest priority. The trainer/supervisor observations of the role-play sessions so far, indicated that doctors put most attention on medical information and less on the emotional response to the needs of patients and families.  
**Discussion:** The courses meet both unarticulated and voiced needs among doctors. The courses have been successful according to participant evaluations and demands for future courses are high. Future challenges include training of trainers/supervisors and teaching of actors. There are also demands and needs to develop similar courses for other professional healthcare workers.

**Abstract number:** P1-157  
**Abstract type:** Poster

### Choosing Treatment Together in Cancer at the End of Life (CHOICE): A Patient Communication Aid

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**Background:** Palliative systemic treatment offers uncertain and sometimes little benefit while treatment burden can be high. Hence, treatment decisions are highly preference sensitive and require shared decision making. Patients need tools that stimulate information exchange in consultations about palliative treatment.  
**Aims:** This study aims to develop and test the feasibility of a communication aid that helps cancer patients to prepare for a consultation about palliative treatment. The aid contains (1) a Question Prompt List with example questions about treatment options patients can ask the oncologist and (2) a Value Clarification Exercise consisting of questions patients can ask themselves to become aware of their values.  
**Methods:** In phase 1, a prototype was presented to patients (n=13), their companions (n=8) and bereaved relatives (n=14) in semi-structured (focus group) interviews. Participants evaluated the content, usefulness and usability of the aid. Interview transcripts were coded in MAXQDA10 software. Based on the findings, the aid was adjusted. In phase 2, feasibility was tested in clinical practice. Patients with incurable cancer (n=20) and a median life expectancy < 1 year were invited to use the aid in a treatment decision consultation. Through post-visit questionnaires and interviews with patients and oncologists the use,

perceived usefulness and usability of the aid were examined.

**Results:** Although somewhat confronting, most phase 1 participants believed the aid to be useful. Further analyses will categorise the reasons participants mentioned. Participants provided valuable suggestions to enhance the content and usability of the aid. Data collection for phase 2 is ongoing (until Jan 2015).

**Conclusion:** Preliminary findings demonstrated that, although confronting, a communication aid aimed at facilitating shared decision making about treatment is acceptable in palliative oncology. The study was funded by Alpe d'HuZes/Dutch Cancer Society.

**Abstract number:** P1-158

**Abstract type:** Poster

## 'It is Difficult to Talk about, but I Think it Can Help me' – A Qualitative Study about Advance Care Planning for Patients with Life-threatening Pulmonary Disease

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**Background and aim:** Advance care planning (ACP) is a tool for communication and mapping of patients' wishes, priorities and preferences for end-of-life care. So far, ACP is not used in any hospital in Norway. In order to prepare for the introduction of this tool, we wanted to explore the views of Norwegian pulmonary patients on ACP.

**Methods:** We conducted three focus group interviews at the Department of Thoracic Medicine in a Norwegian teaching hospital, with a purposive sample of ten patients (52 - 80 years), five of them women. The participants suffered from end-stage COPD, lung cancer or lung fibrosis. They were invited to talk about end-of-life issues and communication preferences regarding these. Analysis was performed using systematic text condensation.

**Results:** The participants' primary need facing end-of-life communication was «the relieving safety». Four underlying themes contributed to this safety. (i) *Good team players:* Both in the health care system and private life, they could provide the necessary courage and setting for these conversations. (ii) *'Give me what I need':* Difficulties in communicating about important matters could give a feeling of loneliness and sadness. There was a common agreement that health care workers should ask all patients about their needs for communication and planning ahead. (iii) *Seize the turning point:* The participants in this study preferred the discussions to be at the time of diagnosis and at the different 'turning points' in the disease trajectory. (iv) *Transparency:* This was important, but difficult to balance. The participants also stressed the importance of using the medical record as a means of communication.

**Conclusions:** Establishing routine ACP for patients with life-threatening pulmonary disease should rest upon relationship building and increased awareness of dramatic turning points during disease progression. Health care professionals can support these patients by emphasising individually tailored communication.

**Abstract number:** P1-159

**Abstract type:** Poster

## Patients' Understanding of Terminology Used in Palliative Care Services

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**Background:** Good communication stipulates that we avoid using jargon. However patients' understanding of terms such as 'Specialist Palliative Care Nurse' and 'Macmillan Nurse' seems variable. Patients who are already known to a Palliative Care Specialist Nurse often ask whether they could see a Macmillan nurse.

As palliative care evolves and the role of hospices has changed to include complex symptom control, the subsequent name change to 'Specialist Palliative Care Unit' seems logical. However patients' understanding of this too seems variable.

**Aim:** To establish the understanding patients have of the terms commonly used in palliative care and ascertain whether the terms we take for granted cause any confusion.

**Methods:** Qualitative semi structured interviews with 20 participants attending palliative care outpatient clinics. Participants had a range of life limiting conditions and prognoses. Patients new to the service and those already known were sampled to identify any difference in their understanding. Interviews were recorded and transcripts were analysed using the principles of thematic analysis.

**Results:** Only 4 patients were able to identify that the roles of Specialist Palliative Care Nurses (SPCN) and Macmillan Nurses were similar. 4 patients felt that the SPCN was the same as the cancer specialist nurse. 5 patients specifically mentioned the Macmillan Nurse being available to provide hands on basic nursing and overnight care.

All participants identified end of life care with the term hospice. More than half did not know what a Specialist Palliative Care Unit entailed. Almost a third thought it was the same as the acute oncology ward or chemo/ radiotherapy unit. Only 3 patients expressed their understanding of the two providing a similar role.

**Conclusion:** There seems to be a real discrepancy between what is meant by these terms used commonly in practice and what is actually understood by patients. This raises serious issues which would benefit from further study.

**Abstract number:** P1-160

**Abstract type:** Poster

## Testing and Evaluating a Complex Intervention in Relation to Dignity and Person Centred Care in the Acute Hospital Setting

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**Background:** Providing person-centred, dignity-conserving care for hospitalised patients is central to many international healthcare policy. The Patient Dignity Question (PDQ) 'What do I need to know about you as a person to take the best care of you that I can?' is a question

designed from empirical research on patients' perceptions of their dignity at end of life to help healthcare professionals understand the patient as a person.

**Methods:** This mixed method pilot study was conceptualised to test the hypothesis that the PDQ intervention could be used to enhance a more person-centred climate for people with palliative care needs in the acute hospital setting, and provide evidence regarding its acceptability. Outcome measures were used pre and post intervention. Primary outcome: Person-centred Climate Questionnaire patient version (PCQ-P), Secondary outcome: Consultation and Relational Empathy (CARE) measure; PDQ feedback questionnaires were used for all participants post intervention, in addition to qualitative interviews.

**Results:** 30 patients, 17 HCPs, and 4 family members participated. Results showed a positive correlation between higher PCQ-P scores and higher CARE scores, indicating that the PDQ can make improvements to a person-centred environment and levels of empathy perceived by patients. The PDQ supported disclosure of information previously unknown to HCPs, which has implications for improving person-centred care. Positive results from PDQ feedback questionnaires were received from all participants.

**Conclusion:** The PDQ has potential to improve patients' perceptions of care, and HCP attitudes. Furthermore, it was well received by participants. The PDQ could be incorporated into clinical practice for the care of palliative care patients in the acute setting to the benefit of personalised and dignified care.

Further research using the PDQ across wider geographical areas, and more diverse settings, is indicated and planned.

**Abstract number:** P1-161

**Abstract type:** Poster

## 'To Just Ask them Is the Easiest Way to Find out...' - Ways of Communication in the Process of Integrating Specialized Outpatient Palliative Care. A Qualitative Pilot Study

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**Background:** Specialised outpatient palliative care (SOPC) needs sensitive and intelligible communication between all participants. To date only little is known about how communication is accomplished in daily practice between general practitioners (GP), patients, relatives and palliative care team (PCT).

**Aim:** This study's aim is to investigate structures of communication that are established within the process of integration of SOPC. The focus is on personal experiences of actors within SOPC, like barriers and difficulties at the point of intersection.

**Methods:** Qualitative study design using purposive sampling. Focused group discussions (4-5-6 participants) with palliative care professionals (n=3 groups), analysis using formulating interpretation (Bohnsack) and mapping technique (Pelz et al.). Open guided interviews with GPs (n=2), analysis using content analysis (Mayring).

**Results:** Healthcare professionals (HCP) define communication as a basis of their work and a process of openness and empathy which succeeds if everyone feels involved. Common problems are seen in a difficult communication in hospitals, 'prescription without communication' and barriers like lack of time and sealing off from communication. PCTs experience communication with GPs as deficient concerning exchange of information and agreements about tasks and functions, which causes feelings of isolation. GPs regard PCT as an important addition to their work, but clarifications of the sphere of activities and assignment of tasks in their cooperation is required. A lack of defining roles and meaning for each other causes dissatisfaction of PCTs regarding communication with GPs.

**Conclusion:** Communication in the process of integrating specialised PC in the outpatient setting needs to be improved when it comes to the process of integrating specialised PC in primary care setting; especially information regarding activities, assignment of tasks and role definition needs improvement.

**Abstract number:** P1-162

**Abstract type:** Poster

## Communication, Key for an Excellent Palliative Care (PC)

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The goals of this presentation are: To highlight the importance of communication in PC team, between the team and patient/family members throughout the end of life process. To identify the factors which influence communication in PC units and in breaking bad news. To identify the barriers that impact directly the effective communication.

**Background:** Communication is the most important component in providing PC especially during the last days of life. Communication plays a very important role in PC especially between staff members (within the multidisciplinary team), between doctor and patient/family members and between the patient and family members.

**Factors which can affect negatively the communication process:** Being not aware of the diagnoses and prognosis make communication difficult because it affects directly to achieve the goal of PC, 'Quality of life until the end'. The absence of a law on the communication of the diagnosis. Deficiency of health culture in the community. Lack of information on PC. Not accepting the truth of the diagnosis until the end of life. Staff burnout, overload. Stress and negative emotions of the patients and their family members.

**Factors which affect communication positively:** Team work, where the support provided to one another is essential to prevent burnout and offer the service with professionalism.

Awareness of the patient/family members on the diagnosis and prognosis of the disease allows an open communication, a quality service and quality of life. Acquaintance of PC from patients, family members, healthcare professionals or community, also affects the mitigation of barriers to provide PC with quality.

**Conclusions:** Communication is key to providing excellent PC and being successful in its provision. Communication in the end of life takes a special meaning. Communication is a complex process and it becomes a difficult challenge in terms of an advanced disease. PC requires verbal communication skills, good listening and a being present.

**Abstract number:** P1-163  
**Abstract type:** Poster

## Preferences toward the Disclosure of Life-threatening Illness and Place of Care and of Death among Patients in a University Hospital in the Philippines

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**Background:** Issues on who to tell the diagnosis first, the patient or the family; the timing of disclosing the diagnosis, whether gradual or immediate; and who should be tasked to disclose, the doctor or the significant member of the family, has long been a point of discussion among health care providers.

**Aims:** The study aims to determine the preferences of the Filipino patients as to full disclosure of their illness, timing of disclosure, person in charge for disclosure, (the doctor or significant family member), preference for place of care and death.

**Methods:** This is a cross sectional analytic study done in a private tertiary university hospital among a total of 80 respondents by guided interview using a validated questionnaire. Chi-Square test, with level of significance set at  $\alpha=0.05$ , was done using SPSS.

**Results:** 30 terminally-ill patients and 50 acutely ill outpatients took part in the interview. Most patients, regardless of whether they have terminal or acute illnesses, have preference for disclosure, for the doctor to perform the disclosure, for immediate disclosure, and for home as the preferred place of care and the preferred place of death. Majority of the patients opted for disclosure as they believe that patients have the right to know the truth about their own condition, that disclosure enables the patients to resolve unfinished business, that being informed of their actual medical condition would enable them to cooperate closely with the health care professionals attending to them, that disclosure relieves them and their family of the burden of unnecessary treatments, and that the patients will eventually learn about the situation anyway.

**Conclusion:** Doctors need to be knowledgeable and skilled in communication as most patients, regardless of state of health and nature of illness, prefer disclosure. Physician should solicit patients' active participation in decision-making as to treatment options and preferences for place of care and of death.

**Abstract number:** P1-164  
**Abstract type:** Poster

## Can we Talk to Dying People?

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**Background:** About 75% of dying people in the Czech Republic are dying in hospitals. While physical ailments can be solved by medication quite easily, there is no pill to solve patient's questions, sadness, loneliness and fear.

Perhaps this is the reason why we are afraid of talking to dying people and to their next of kin. We are not able to solve this kind of pain so easily.

**Aims:** The main aim of this study was to identify satisfaction in the end of life of patients or their family members (if there was no possibility to speak directly with the patient) about communication with attending physician.

**Methods:** Semi-structured qualitative interviews about embarrassments in communication in the end of life were conducted with patients or next of kin from 2010 to 2012. Interviews were recorded, transcribed and analysed using framework analysis.

**Results:** 19 participants were recruited in total. Interviews were conducted in 11 cases with patients and in 8 cases with next of kin. Statements of patients and family members were surprisingly similar. Both groups were not properly informed about on-going death. Physicians communication was usually limited to test results and current health condition. Doctors spoke only about curative therapy, they did not offer possibility of palliation. In many cases was said, physicians showed no emotional or spiritual support. In some cases was emotional or spiritual support very poor. All patients reached a verdict that doctors were short of time to communicate with them, although for all patients communication was essential to gain confidence.

**Discussion:** About the reason why patients were not properly informed, they did not have opportunity to prepare for death and to part with family. About the reason next of kins were not properly informed about on-going death, they were not prepared for bereavement and made a complaint. Consequently, health workers are losing credibility.

**Abstract number:** P1-165  
**Abstract type:** Poster

## Decisions Findings Process Near the End of Life: A Survey in German Paediatric Oncology and Intensive Care Units (ICUs)

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**Background:** Decision findings near the end of life is always ethically challenging for a medical team, especially in case of children and adolescents. We designed a survey to discover how these decisions are made in Germany, how the process is structured and which impact it has on the team, particularly how much these decisions burdens the team members and if they arouse conflicts.

**Methods:** An anonymous online survey was sent to physicians, nurses and psychologists both of oncology and intensive care units from 32 different German hospitals.

**Results:** A total of 77 responses was obtained (response rate 26,10%) and 2/3 of them from oncology units (68%). The most common procedure by far (80,52%) was to find a position within the medical team first before accosting to the parents. Working with a clinical ethic commission occasionally or often was stated by 35,6 %. We detected a significant positive effect on the communication structure when ethic commissions or neutral observers were included in the decision making process. Nurses were not in all hospitals involved in decision making. On the question how often conflicts during the decision making communication strained the team, one third answered often or always. We found conflicts in all ranks:

between professional categories, between hierarchical levels and between individuals.

**Conclusions:** Decision making near the end of life in paediatrics are straining and full of conflict potentials and our findings suggest that structuring the process may be helpful and respectful inclusion of all professions represents an important part of this.

**Abstract number:** P1-166  
**Abstract type:** Poster

## Issues Discussed at Formal Family Meetings in a Specialist Palliative Care Unit

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**Introduction:** Formal family meetings (FFM) are vital in maintaining good communication between staff, patients, and families in a specialist palliative care unit (SPCU). Published research examining the content of FFM discussions is limited. This study aims to identify issues discussed at FFMs, examine the influence of factors such as patient participation, and consider issues discussed at multiple FFMs for a single patient.

**Methods:** The records of a purposive sample of FFMs in a SPCU over a 5 month study period were examined. The sample included an equal number of FFMs with and without patient participation, and all patients who had multiple FFMs. Patient demographics and basic details of the FFMs were recorded. Conventional content analysis was performed on the documented discussion. Issues identified were examined for observable patterns.

**Results:** 33 FFMs were analysed; 10 with patient participation, 10 without, and 13 multiple FFMs. The reasons for nonattendance were personal preference (50%) and unfit medically (50%). Prognosis was discussed in every FFM without patient participation but only in 30% of FFMs with patient participation. Symptoms at the end of life were never discussed with the patient present. At multiple FFMs there were increased discussions on medication concerns, dissatisfaction with care and family/patient well-being, as well as an increase in emotional expression of the family. Overall medical condition, family's understanding of the disease, and symptom assessment and management were the most common themes irrespective of patient factors.

**Discussion:** Discussions on end of life symptoms and prognosis in the patient's presence can be particularly emotive for families. This is reflected in our study by a decrease in these discussions with patient participation and is consistent with published literature. However, addressing these issues is vital in providing optimal care.

**Abstract number:** P1-167  
**Abstract type:** Poster

## On the Way to Advance Care Planning? The Practice of Consultation for Advance Directives in a German Region

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**Background:** Although advance directives (ADs) are legally binding in Germany, their prevalence and quality is often insufficient. Comprehensive Advance Care Planning (ACP) programs are, apart from the pilot project *beizeiten begleiten*, still not widely implemented in Germany. There is, however, an increasing number of organisations and individuals offering consultation for ADs. So far, there is hardly any knowledge about their consulting profile and thereby the quality of ACP in Germany.

**Aim:** To assess the current status of organisation, actual practice and possible improvement of AD consultations by different professional groups compared to international ACP programs as best practise model.

**Methods:** A pilot study using an electronic questionnaire (Likert-Scale) completed by 198 consultants (notaries, hospiceworkers, nurses and general practitioners) in the region of Munich.

**Results:** The structure and content of AD-consultations differed between and even within the professional groups. Due to within-group variability, it was not possible to describe clear consulting profiles for each group. Nevertheless, some focuses could be detected in the groups: A typical consultation is initiated by a healthy (62-70%), 61-80 years old (57-90%) consulted individual herself (61-100%). A consultation takes up to 30 minutes (43-57%) and includes 1-2 meetings (48-60%). 48-97% of the consultants inform about hydration, terminal illness, irreversible unconsciousness. 53-85% suggest to invite the future legal representative, 53-91% report positive experiences of such an involvement. Emergency plans are created only by 0-24% of the consultants.

**Discussion:** These results show that the AD consultations do not yet fully meet the quality criteria of international ACP-programs (e.g. initiate conversations, ACP process with several meetings, participation of future legal representative, planning for emergency).

**Conclusion:** It underlines the need for more comprehensive ACP-programs.

**Abstract number:** P1-168  
**Abstract type:** Poster

## The Diverse Impact of Advance Care Planning (ACP): An Anthropological Follow-up Study on the Experiences of Patients and Relatives

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**Background:** ACP is a discussion between patients, relatives and health care professionals about the patient's concerns and preferences for future care, aiming to guide health care decisions at the end of life (EOL). However, more nuanced knowledge about the long-term impact of ACP is required.

**Aim:** The aim of this study was to explore long-term consequences of ACP for patients and relatives.

**Methods:** The study included 11 semi-structured interviews with three patients and eight relatives one year after participating in ACP. Interviews were recorded, transcribed, and analysed, drawing on anthropological theories on the social construction of patient autonomy, challenging the universal applicability of ACP.



**Results:** Despite a small sample, the study reveals great diversity in both patient and relative experiences of ACP.

Some felt 'relieved', 'more secure' and more in control, because the patient's preferences had become known. For a few, ACP had led to open communication rather than 'beating around the bush', to spending more quality time together, and to feeling 'more prepared' for death. However, others perceived ACP as irrelevant. Some stated that the patient's wishes had not been met regardless of ACP. Others felt that EOL questions cannot be realistically considered until 'you're right in the middle of it' since so many factors are involved. In one case, participating in ACP had led to a patient-relative conflict, resulting in illness and EOL issues being 'tucked away'.

**Conclusion:** This study shows that ACP carries the risk of being inconsequential or even damaging to communication. The study thereby challenges previous research which mainly emphasises ACP as a valuable tool to optimising EOL care.

This study stresses the importance of awareness of the highly individual nature of preferences and needs of patients and relatives regarding information, involvement, and communication about EOL care.

The study is funded by the Danish Cancer Society.

**Abstract number:** P1-169

**Abstract type:** Poster

## Differences in Preferred Place of Care and Place of Death Between Cancer and Non-cancer Patients in Palliative Trajectories

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**Background:** Congruence between preferred and actual place of care (POC) and place of death (POD) is considered an essential component in end-of-life care. Existing literature on this subject is limited and based mainly on cancer patients. As a result, there may be a tendency to apply knowledge from cancer to non-cancer settings. Hence, knowledge is needed to clarify if patients with non-cancer diagnoses have different preferences than cancer patients regarding POC/POD.

**Aim:** To investigate possible differences in preferred POC and POD between cancer and non-cancer patients in palliative care trajectories.

**Methods:** To identify possible differences in preferred POC/POD, three groups of patients are included in this study. Patients with heart failure, lung disease or cancer respectively participate in a prospective randomised controlled trial testing feasibility and possible advantages of *Advance Care Planning* (ACP) in a Danish context. Participating patients are asked about preferred POC/POD in the baseline questionnaire of the ACP study. Eligible patients with an estimated lifetime of 6-12 months are included. The first 40 consecutive patients from each of the three diagnostic groups will be included in the present study. The inclusion of patients began November 2013 and ends May 2015. Until now 78 patients have been included in all. Relevant regression models will be used to compare the preferences, allowing adjustment for age and gender. The project is founded by The Danish Cancer Society and Trykfond.

**Results:** Data of patients' preferences regarding preferred POC/POD will be presented.

**Conclusion:** Knowledge of preferences regarding POC and POD among patients with various diagnoses and at an individual level is imperative in improving quality of end-of-life care. This study adds awareness to the possibility that preferences regarding POC and POD may differ between patients with different diagnoses and thus may help target future research appropriately.

**Abstract number:** P1-170

**Abstract type:** Poster

## Communication with Cancer Patients

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**Background:** Effective patient-physician communication is at the core of health care, especially for cancer patients. The importance of education of communication skills to medical students have been recently acknowledged in medical universities in Iran.

**Aims:** To identify what cancer patients expect from communication with their oncologists.

**Methods:** Non-structured and experimental medical interview with more than 2000 patients with advanced staged of cancer who were referred to palliative care clinic from 2011 to 2014.

**Results:** The following list of recommendation for physicians has been generated based on the most frequent points mentioned by the patients.

- 1-In presence of patients, it is preferred to directly address them rather than their relatives
- 2-Let the patients talk about themselves; physical problems, emotional feelings, spiritual suffering and even economic problems. The physicians cannot solve all these problems but by being heard makes the patients comfortable.
- 3-If the patients need and want to know about their diseases the physician should completely explain for them.
- 4-The patient should be examined in each visit even if the physician thinks that it is not required.
- 5-Although the whole truth about the disease or its outcome might not be revealed to the patients, any lie should be avoided.
- 6-The physician shouldn't be indifferent while telling bad news to the patient.
- 7-The physician should avoid telling something to the patient which makes him/her feel remorse.
- 8-The physician should avoid giving the patient a define time limit for their living.
- 9-The patient should be allowed to try their preferred unconventional treatment even if the physician found them unhelpful.
- 10-Use of humor in communication with the patients is recommended.

**Conclusion:** Education of communication skills should be part of curriculum of medical students and residents of all specialties.

**Abstract number:** P1-171

**Abstract type:** Poster

## Sharing the Diagnosis of Dementia: Breaking Bad News to People with Intellectual Disabilities

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**Background:** Following previous research findings that existing models for breaking bad news to patients who have a life-limiting illness are inadequate in meeting the needs of people with intellectual disabilities (ID), a 2 year study into breaking bad news to this group of patients/relatives resulted in the development of a new model for breaking bad news to people with ID, which was presented at the EAPC Conference 2011 in Lisbon. The model is based on the finding that bad news situations are usually complex and are made up of lots of different chunks of knowledge and information; the acquisition of these chunks is a non-linear process that can be unpredictable. Building someone's foundation of knowledge and understanding is central to the model. It has been used successfully in practice; however, it is unclear how this can be applied to people with ID and dementia. UK and European dementia strategies specify that everyone is entitled that everyone is entitled to know of their diagnosis.

**Aim:** To explore whether the new model for breaking bad news can be used effectively in sharing a diagnosis of dementia with people with ID.

**Methods:** The model was applied to people with dementia and ID as follows:

- (1) the literature on dementia and breaking bad news was analysed;
- (2) theoretical assumptions were made based on the model itself;
- (3) the model was applied in real-life situations.

**Results:** Through a case study, we will present how the model for breaking bad news was used. A man with ID had not been told about his dementia diagnosis, nor about his mother's terminal cancer. The model was helpful to both the client and his support staff in helping him understand and cope with his changing situation.

**Conclusion:** This initial exploration of the use of the model has promising results, but a study is now underway to investigate further how people with ID and dementia can be best supported in their need for understanding.

## Development and organisation of services

**Abstract number:** P1-172

**Abstract type:** Poster

## CASA Study: Care and Support Access - Implementation of a Palliative Approach for HIV+ Young Men who Have Sex with Men to Improve Engagement and Outcomes - Preliminary Results

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**Background:** Early implementation of a palliative approach (EIPA) can improve chronic disease management. We target a subset of people living with human immunodeficiency virus (PLWH) to demonstrate how EIPA can be introduced for non-palliative specialists. HIV positive young men who have sex with men (yMSM) remain at risk for poor outcomes facing myriad impediments to achieving disease control.

**Methods:** EIPA, facilitated by an educational intervention combining iterative teaching and on-site coaching, patient representatives and emphasis on self-care for staff used to introduce key elements of PC into the management of HIV disease. The interdisciplinary team guided by patient-family needs, focuses upon goal-setting, symptom management, and communications skills. We intend to:

- 1) determine the impact of EIPA to improve patient-centered care;
  - 2) describe the impact of EIPA upon yMSM relative to decreasing viral suppression, impact on mental health and quality of life (QOL); and
  - 3) describe the impact of EIPA upon staff with regard to reducing stress of providing care. Mixed methods and a quasi-experimental design are used to compare outcomes in a longitudinal sample of 204 yMSM from two outpatient clinics in one urban U.S. city.
- Results:** In the era of HIV disease control preliminary data shows a co-morbid population. Of 57 yMSM currently enrolled 66% are under 30. The majority self-identify as African-American (75%), Hispanic (11%), and mixed (11%). Thirty-two percent have a high school education; 17% have less. Thirty-two percent are employed; 16% are disabled. Despite the young age, 30% have been incarcerated. 74% report skipping medication, a third have missed at least half of their scheduled appointments. Drug use/abuse history: marijuana (80%), cocaine (26%), amphetamines (11%), alcohol dependence (23%).

**Conclusions:** EIPA is being tested to improve outcomes in patients known to be non-adherent. Staff are evaluated for stress relative to care delivery.



**Abstract number:** P1-173  
**Abstract type:** Poster

## The Impact of Dragos Nurses on the Quality of Life of Pediatric Patients

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**Context:** In Romania, annually, approximately 5.000 children and young adults are diagnosed with cancer. 80 % from these patients are coming from all over the country to receive curative treatment in 5 different public hospitals. Project idea came as a response to a need identified in a few hospitals in Bucharest, Romania, by the team Dragos Nurse. The role of Dragos nurse will be to meet the needs of children and young people with advanced cancer, together with support and guidance for their families and carers.  
**Aim:** Dragos nurses team represents the pediatric hospital team created with the purpose of delivering high quality Palliative Care to pediatric patients and their families, while receiving oncologic curative treatments. This paper aims to present the impact of the Dragos nurses team on the symptom control of beneficiaries.  
**Method:** quantitative retrospective study, conducted between October 1<sup>st</sup> 2012 and September 30<sup>th</sup> 2014, on 174 patients. The data collection is based on the patients charts and the nurses reports.  
**Results:** Number of patients: 174; number of nurses intervention: 2565; number of doctors intervention: 756; number of social worker interventions: 455. The SAV scores dropped from an average 6 to zero. (From 174 patients, 90 had pain and for 85 of them the pain dropped to zero). 90% of the most frequent symptoms (oral lesions, anemia, anorexia and nausea) had been controlled.  
**Conclusions:** Dragos Project had been a great challenge for every team practitioner involved, because of the rigid mentality in the Romanian health system, lack of resources and time, number of patients, the lack of palliative care understanding. The presence of Dragos Nurses in the hospital, involved controlling the previous symptoms in a very high percent and the improvement of the quality of life for the patients and their family members, the team being a real support for them.

**Abstract number:** P1-174  
**Abstract type:** Poster

## Why do Specialist Palliative Care Patients Come Back into Hospital? A Retrospective Review of the Readmissions and Re-attendance to Hospital of Patients Seen by a Hospital Specialist Palliative Care Team

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Avoidance of 'inappropriate' hospital admissions is a strategic aim of NHS England. The aim, supported by advance care planning initiatives, may help individuals avoid medically futile hospital interventions especially towards the end of life. However, the term 'inappropriate' is poorly defined and will be person and illness specific. This review explores the individual reasons for hospital readmission and re-attendance for patients seen by our hospital Specialist Palliative Care (SPC) team between October 2013 and February 2014. The review was undertaken in August 2014. Hospital electronic notes were used to identify reasons for readmission/attendance, which were then judged as potentially 'appropriate' if they involved (a) treatment of reversible deterioration (b) provided recognised symptom management or (c) resulted in death where hospital was documented as the preferred place of care. Between October 2013 and February 2014, 96 of the patients seen by the SPC team were discharged from hospital. At follow-up 19 (20%) had received further hospital treatment. Readmissions/attendances were deemed appropriate for 14 patients and included surgical review of bowel obstruction, treatment of neutropenic sepsis, pleurodesis, blood transfusion, and dying in their preferred place of care. For 2 patients, readmission may have been inappropriate due failure of community care. 3 patients were labelled inappropriate as the reasons for re-attendance could not be determined from the data recorded. Thus only 5 (5%) of the 96 discharge patients had potentially inappropriate readmissions. The limitations of this audit include its size, its retrospective nature and judgement of appropriateness of readmission/attendance by a single author. Also the audit did not assess any patient view of their hospitalisation. However, it highlights that SPC patients may benefit from hospital attendance in certain circumstances, a fact that must not be lost in the drive to reduce hospital admissions.

**Abstract number:** P1-175  
**Abstract type:** Poster

## Integration of Palliative Care into Comprehensive Cancer Centers in Germany - Where Do we Stand?

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**Background:** The extent of integration of palliative care (PC) in German Comprehensive Cancer Centers (CCC) funded by the German Cancer Aid (DKH) is unknown.  
**Aims:** The purpose of this study was to investigate clinical, research and teaching similarities and differences of PC in CCC structures in Germany.  
**Methods:** Structured quantitative and qualitative interviews were performed with the heads all PC departments. Additionally an external perspective was described by 11 persons who were not directly involved in PC, but represented inpatient and outpatient care. Interview questions were generated after a comprehensive literature search and discussion with PC experts. The interviews were conducted from May to August 2014.  
**Results:** At the time of the survey 13 CCC with 14 different sites in Germany (1 CCC had 2 university hospitals) were funded by the DKH. Of these, 12 sites had a palliative care unit (86%). PC consulting services were identified in 11 CCC (79%). Patient reported outcome measures were routinely used in 11 (79%) sites. Tumor board participation of PC specialists is not provided in 3 (21%) institutions. The majority of centers described participation problems due to staffing shortage. In 7 sites (50%) defined criteria to integrate PC into CCCs were available; in 10 (71%) standard operating procedures (SOP) exist. In the last five years 5 PC departments (36%) were invited to participate in research projects of other departments of the CCC, 10 sites (71%) had started own PC research projects. Professorships in PC were available in 5 CCCs (36%). PC training courses were provided in all PC departments.  
**Conclusions:** The extent and depth of PC integration in the 14 CCC sites is rather heterogeneous. The gained data will foster the development of a 'Best Practice Model for Palliative Care Integration into the German CCC'.

**Abstract number:** P1-176  
**Abstract type:** Poster

## Second Last Stop? A Study of Discharges of Seriously Ill and Dying Patients from our Hospice

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**Background:** 'Our Hospice ward' (HW) is a palliative unit with 12 beds for seriously ill cancer patients. The length of patient stay is limited due to conditions of funding for hospital wards and the wish to serve a larger number of patients. All patients are first given a 14-day stay. After 2 weeks, pts with a life expectancy of more than 2 weeks who are unable to stay in their homes are transferred to a Nursing Home. These discharges represent a tough situation for the pt and their family.  
**Objectives:** To review the discharges of patients from HW and the duration of life for patients discharged from HW to nursing homes.  
**Patients and methods:** All pt discharged from HW from 2005-2011, a total of 1794 patients.  
**Results:** The average length of stay at HW was relatively stable during the years 2005 - 2011 and varied from 14.6-17.8 days. The percentage of patients that died at HW each year varied from 54.1%-62.8%.  
Among the patients discharged alive, an average of 53.3% were discharged to their homes, 21.4 % were sent to other hospital wards and 16.9 % were moved to nursing homes. Of these 5.8% died within 8 days after the transfer, 20% died within 14 days, 28.3% died 15-30 days and 51.7% lived longer than 30 days after the move. A total of 80% lived longer than 14 days and 33% lived for more than 2 months after the transfer from HW.  
**Discussion:** This study shows that the number of patients transferred to nursing homes is only about 20 %. More than 80 % of the patients transferred to nursing homes lived longer than 14 days after the move and more than half of the patients lived longer than a month. Although a move to a nursing home may cause negative reactions among patients, their relatives and the staff at HW, this must be weighed against the fact that many of these patients live for relatively long periods after the discharge and that discharging them will give more patients the benefit of the special expertise that HW offers.

**Abstract number:** P1-177  
**Abstract type:** Poster

## What Do We Know about Different Models of Specialist Palliative Care? Findings from a Review of Reviews

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**Background:** Expansion of palliative care services internationally means robust evidence is required to support policy and service commissioning decisions. The advantages and disadvantages of different models of palliative care need to be identified. Exploration of the most effective components of these models is also needed.

**Aims:** This review of reviews identifies the potential strengths and weaknesses of different models of palliative care and their relative appropriateness for various populations and patient groups.

**Methods:** A comprehensive search of 7 databases from 2000-2014 for English language systematic and narrative review level evidence was undertaken. Reference lists of included reviews were scrutinised to identify further reviews. Reviewers independently screened titles and abstracts for relevance using pre-determined inclusion criteria. Two reviewers independently extracted data for each included study. Methodological quality was assessed using the AMSTAR tool. Narrative synthesis was undertaken.

**Results:** From 16141 papers identified, 8 medium - high quality reviews of specialist palliative care were included. Most evidence related to models of palliative care delivered in the home. Heterogeneity in descriptions of models of palliative care and lack of detailed description of individual models made appraisal and comparison difficult. However, evidence suggests that different models may be appropriate depending on local priorities, population need and existing services. Limited evidence exists about the cost-effectiveness of each model. Given methodological limitations, it was not possible to identify the best and worst performing models or potential beneficial components of models.

**Conclusion:** Better reporting of models of palliative care and further primary research is needed to identify beneficial models / components of models and their cost-effectiveness. Co-funded by the European Union (FP7-Health-2012-Innovation, grant agreement 30614)

**Abstract number:** P1-178  
**Abstract type:** Poster

## Healthcare Professionals' Perspectives of the Role of Specialist Palliative Care in a Major Trauma Ward: A Qualitative Study

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**Background:** Major trauma centres are regional centres of excellence, improving survival and outcomes for patients across England. However, 27% of major trauma patients will not survive their injuries and a significant proportion will survive, but with permanent disabilities. A literature review found a few studies on palliative care and the Trauma Intensive Care Unit, in a US setting, but this is the first study to examine the role of specialist palliative care in major trauma in the UK. Palliative Care is known for its focus on impeccable assessment, relief of suffering, and support for the dying and their carers. Currently, little is known about the best model for providing this type of care in a major trauma centre.

**Aim:** To explore the perspectives of doctors, nurses and allied health professionals on a major trauma ward regarding the potential contribution of specialist palliative care.

**Methods:** Semi-structured face-to-face interviews were conducted among a purposive sample of healthcare professionals working on a major trauma ward in an inner London teaching hospital. Data was analysed using the Framework approach.

**Results:** Nine healthcare professionals were interviewed. Participants reported instances where end-of-life care was felt to be sub-optimal. Moreover, they stated they did not feel confident or comfortable in care for the dying. Participants reported they had little experience working with the specialist palliative care team and described common barriers to referral. Other themes emerging from the interviews included prognostic uncertainty, decision-making at the end of life and concerns about communication with patients and families.

**Conclusions:** Major trauma professionals recognise the importance of caring for the dying and the place of palliative care. Specialist palliative care has the potential to enhance care experiences and reduce staff stress, but the best model and resource implications for this need further research.

MSc research funded by ICHNT.

**Abstract number:** P1-179  
**Abstract type:** Poster

## Ten Principles of the Economic Case for Specialist Palliative Care

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**Aim:** Numerous studies have documented the impact of specialist palliative care (SPC) on costs, yet no one has completely articulated the economic imperative for SPC, and how it could be aligned with the clinical-moral imperative. A 'business case' is needed in which the indirect benefits for institutions are linked to the direct clinical benefits for patients, especially in the US and other capitalistic or mixed healthcare economies.

**Approach:** We reviewed published studies of healthcare financing and SPC impact. We incorporated insights from our hands-on work on program financing with hundreds SPC programs in the US over the past 15 years.

**Results:** We identify, articulate and provide evidence for ten principles which together form a business model for SPC. The first and foundational principle is SPC has a demonstrable

positive impact on patient-centered outcomes. The second is that hospital utilization tends to dramatically increase toward the end of life. The third and fourth principles describe the implicit and explicit financial disincentives for over-utilisation of hospital care. The fifth and sixth principles describe the impact of inpatient and community-based palliative care on utilisation and costs. The seventh principle is that SPC teams are often inadequately staffed and poorly resourced. Principles 8 and 9 demonstrate the 'return on investment' for institutions adequately staffing inpatient and community based programs. And the final principle is that all SPC programs can use published and internal data to demonstrate these principles within their own institutions and communities. We point out methods and analytic tools that are available to help.

**Conclusions:** With this framework, SPC program leaders can articulate and demonstrate the benefits that would accrue to hospitals and payers. While most relevant to the hyper-fragmented, capitalistic US health care system, most of these principles also apply in other countries.

**Abstract number:** P1-180  
**Abstract type:** Poster

## Barriers to the Development of Palliative Care in Europe. Data from the EAPC Atlas of Palliative Care in Europe 2013

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**Background:** We define barriers to the development of Palliative Care (PC) as those factors which prevent proper and comprehensive provision of PC in a country.

**Aim:** To identify barriers reported by PC experts in the EAPC Atlas of Palliative Care in Europe 2013.

**Method:** A specific question was developed for the survey: *Please, list in order of importance the three main barriers to the development of palliative care in your country at the present time.* The questionnaire was submitted to PC leaders of 53 European countries, previously identified through National Associations, with a response rate reaching over 80%. Responses were subjected to a comparative content analysis and categorised by three different referees in open coding first to find out the barriers themselves, and in axial coding afterwards to determine the origin of the identified barriers. Concordance index was calculated and agreement achieved by consensus techniques in case of disagreement.

**Results:** 153 barriers were reported: 92 were governmental, 41 related to the professional's world and 20 to socio-cultural factors. Amongst the varied barriers identified within the governmental category, the reported obstacles refer to 'Health policy' (n=39), 'funding' (n=27), 'legislative' (n=11), 'opioids' (n=9) and 'lack of certification in PM' (n=6). In the professional domain, 'lack of education' (n=23), 'lack of integration' (n=10) and 'work capacity' (n=8) were identified. Socio-cultural barriers include 'lack of awareness' (n=14), 'cultural obstacles' (n=5) and 'opiophobia' (n=1).

**Conclusion:** Despite the continuous efforts and claims to put PC into political agendas, still professionals report a great number of barriers related to health policy, funding and legislation.

**Abstract number:** P1-181  
**Abstract type:** Poster

## Bridge over Troubled Waters: Co-ordination of SPCS across Boundaries

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**Background:** Patients known to specialist palliative care services (SPCS) can be admitted to hospital without hospital palliative care nurse specialist (HPCNS) knowing they are there. If not formally referred, then support is not available during stay.

**Aim:** To identify patients with SPC needs, admitted to hospital without notification or referral to HPCNS. All patients known to SPCS should be notified to HPCNS on admission to enable SPCS input and support.

**Method:** Lists of A&E attendances, inpatient GSF alerts and informal notifications to admin staff, were scrutinised for patients known to SPCS in community, care home or hospice. Key enablers (GSF registration; Advance Care Planning (ACP)) already in place; the date last seen or spoken to and outcome or discharge method recorded.

**Results:** 21 admissions, already known to SPCS elsewhere, were identified by this method. 50% were notified to HPCNS by SPCS elsewhere. Admission method: 10 (48%) via A&E, 6 (29%) by GP via Emergency Admissions Unit, remainder unknown. 9 (43%) referred by ward staff to HPCNS, 4 (19%) notified to from other sources, 8 (38%) present in hospital without HPCNS being aware. If notified or referred: 3 (23%) on day of admission; 8 (62%) within 24 hrs; one within 72hrs and one after this. All 21 (100%) were GSF registered, one had an ACP and 15 (71%) had recorded preferred place of care.

**Conclusion:** Where SPCS alerted HPCNS of patient's admission then patient received support during stay. Scrutiny of GSF alerts would enable HPCNS to be aware of those SPCS patients admitted to hospital, where admission was unknown, providing all were GSF registered. This highlights the importance of GSF registration for patients known to SPCS, where appropriate. An admission flowchart was developed to streamline the process of notification of admissions to hospital where these are known and the creation of a new TRANSFORM Team is increasing identification of those known to be GSF registered and also those requiring SPC input.

**Abstract number:** P1-182  
**Abstract type:** Poster

## "Can you Come Right Now?" Development of a Palliative Rapid Response Ambulatory Service in a Comprehensive Cancer Centre

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**Introduction and background:** Innovations in cancer care have resulted in patients with metastatic cancer having greater access to life-prolonging treatment. Increasingly oncology treatment is provided in ambulatory care settings. Many of these patients suffer severe symptom distress requiring specialist palliative care. Health promotion models advocate early assessment and introduction to specialist palliative care services for patients with metastatic disease. The Department of Pain and Palliative Care (DPPC) at Peter MacCallum has developed a Palliative Care Rapid Response Team (RRT) in ambulatory care.

### Objectives:

To provide timely access to palliative care within ambulatory care settings integrated into the acute oncology model

To improve follow up for patients and families by facilitating coordination and maximising continuity of care for patients with complex needs.

**Method:** The DPPC at Peter MacCallum developed a palliative care rapid response team staffed by physicians and a nurse practitioner.

### Results:

Within a 12 month period there was a 40% increase in the number of referrals received. Patients were referred earlier in their disease trajectory. More than 75% patients referred to RRT reported pain moderate (4 to 7) to severe (8 to 10) pain scores using the Numerical Rating Scale at time of first presentation. Patients assessed by the RRT were more likely to have their next of kin present at time of initial presentation compared with patients referred from inpatient areas. The RRT also reviewed patient who required admission to hospital before they arrived in inpatient areas. This facilitated direct collaboration with treating oncologists and implementation of palliative management plan prior to formal admission procedure. **Conclusion:** The introduction of the RRT increased access to specialist palliative care to patients with metastatic disease undergoing cancer treatment.

**Abstract number:** P1-183  
**Abstract type:** Poster

## Delivering a Multi-stranded Information and Support Service in the Community

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In 2008 following a multi-disciplinary discussion about reaching out to the community, the Hospice was the first in the UK to launch its innovative information and support service the Hospice Outreach Project 'HOP' utilising a custom truck. The premise was to develop a multi-stranded service which would offer drop-in information, support and advice for people that were ill, bereaved or worried about someone who was...

### Aims:

Widen access and increase referrals

Provide high quality health and wellbeing information

To offer drop-in information, support and advice in the heart of the community via a alternative model

Break down some of the taboos surrounding death and dying

### Design:

Develop mobile and static strands operating 5 days a week

Staffed by full time Team Leader, part time Information and Support Specialist (registered nurse and registered social worker), full time Driver/Support Worker and 15 trained Information Service Volunteers - this skill mix provided a high quality, low cost model of operation. Working collaboratively with other organisations sharing resources to access harder to reach groups

### Results:

2008-2009	2009-2010	2010-2011	2011-2012	2012-2013	2013-2014
629	1076	1246	1678	3214	5014

[Year on Year Contacts]

The contact figures for the Information Service demonstrate that the public want to engage with the hospice and utilise the services provided. Analysis of the data indicates that elements of the service are providing a service to different groups of people than those who have previously accessed the hospices services.

### Conclusion:

The Information Service is recognised as a valuable model that widens access to services for local community

The mobile and static mix offers optimum flexibility and accessibility

Volunteers are vital to the continued existence and development of the service

Future developments include 7 day working, further collaborative working.

Sharing innovative practice not only builds bridges it develops services for those who need them the most.

**Abstract number:** P1-184  
**Abstract type:** Poster

## Implementation of Palliative Care in Danish Hospitals through Local Intervention Projects - An Evaluation

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**Background:** Palliative care is not sufficient implemented in Danish hospitals. This project is carried out to improve the quality of palliative care to patients with life threatening diseases during contact to hospitals. Eight local projects based on concrete palliative interventions were generated and implemented in eight Danish hospital departments during 2012-2013. Local project managers were responsible for individual local projects, supervised by a central national project manager and a professional network of local project managers.

**Aims:** The projects were evaluated in total to develop new insight about preconditions for implementing palliative care in a hospital context and to examine the contribution of concrete palliative care interventions to improve palliative care in hospitals.

**Methods:** The evaluation was inspired by responsive programme evaluation considering the project as one program. Seven focus group interviews with staff, two focus group interviews with project managers and twelve individual interviews with heads of participating hospital wards were carried out and analysed by use of Grounded Theory Method.

**Results:** The informants found it very meaningful to implement bottom-up initiated clinical projects. Palliative interventions, a systematic approach and local foundation served as a booster for improving palliative care in local hospital wards. The implementation was guided by passionate project managers, however in lack of time to undertake their tasks, among this time to clarifying dialogues with participants to promote active participation. Contextual factors as time and organisational culture of change were widespread barriers during the implementation process.

**Conclusion:** Implementation of palliative interventions based on local ideas and efforts combined with central initiative and support complementing existing local resources is a practicable and valuable method to improve palliative care in hospitals.

**Abstract number:** P1-185  
**Abstract type:** Poster

## Preliminary Results of a Pilot Study of Quality Indicators in a Colombian Home Care Program

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**Background:** According to the WHO, non-communicable diseases (NCDs) cause 71% of deaths in Colombia. Patients with NCDs could benefit from Home Care in late stages. Health provider companies have Home Care Programs (HCP) to treat acute, chronic and recently palliative care patients, in an effort to use resources more efficiently. The Ministry of Health (MOH) mandates HCP to monitor regularly quality indicators. This poster describes the services using a set of quality indicators developed by the Universidad de la Sabana.

**Objective:** To evaluate and report on the quality of the services provided by a HCP in Bogota, Colombia.

**Method:** Data from all patients admitted to the HCP between January 2013 and September 2014 was analysed using the following indicators:

*Number of patients serviced:*

*Rejection:* % of patients who did not meet the criteria for admission in the program

*Hospital Admission:* % of patients admitted to the hospital

*Adverse effects:* % of patients who reported adverse effects

*Complications:* % of patients who reported complications

*Complaints:* % of patients or caregivers who registered a complaint

*Satisfaction with service:* Measured by a follow up phone call after each consult on a level from 0 (very dissatisfied) to 5 (very satisfied)

Descriptive analysis were performed.

**Results:** Total patients admitted was 6,155. An increasing admission trend was observed (237 vs 493 first and last month respectively). The following averages for each indicator were observed: No Access 1.3; >21% of cases were rejected; 8 time between initial request and consult was 1.6 hrs; 2% of the patients were admitted to the hospital and 1.3% adverse events were reported. The % of cases which presented complications and complained was < 1. Percentage of patients who reported satisfied or very satisfied with the HC program was >93%.

**Conclusions:** A Home program with a mix model can produce satisfactory quality indicators that suggest that can be replicated in different scenarios.

**Abstract number:** P1-186  
**Abstract type:** Poster

## Making the Best of Clumsy Co-ordination: Improving the Co-ordination of Care for End of Life Patients

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**Background:** An area in the North of England (pop 235,000) already supports identification and co-ordination of patients approaching End of Life through Gold Standard Framework (GSF) in primary care and acute hospital. Attempts to unite these processes are hampered by the lack of an appropriate IT co-ordination system.

**Aims:** To facilitate co-ordination of care by compiling a central cross-boundary register of patients recognised to be approaching end of life, sharing Advance Care Planning and smooth transition for patients changing care settings.

**Method:** The integrated Specialist Palliative Care Services (SPCS) compiles a locality wide end-of-life care register by collating information from the hospital, hospice, GP surgery and care homes. With consent all patients are flagged on the hospital patient administration system for identification and tracking on admission to hospital allowing SPCS to identify the patient's needs, wishes and preferences, facilitate timely discharge to the patients place of choice and support patients and families. Community teams are informed when patients are identified in hospital. Gold Standard Framework Care Plans have been introduced in hospital



and community to ensure patients' needs are assessed consistently and that assessments follow the patient reducing the need for replication of work.

**Results:** The SPCS now holds a cross-boundary list of all patients thought to be approaching end of life (891). For those who die, 94% have a documented Preferred Place of Care at the time of death, and 85% of those achieve it.

**Conclusion:** The existence of a central cross-boundary end-of-life care register improves communication between different health care providers enabling patients to be cared for and die in their place of choice. Work is on going to make this available on a fully accessible IT system.

**Abstract number:** P1-187  
**Abstract type:** Poster

## Improving Clinical Palliative Cancer Pathways

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**Background:** Spring 2014 we started a project to evaluate and improve quality of the palliative cancer pathway in the hospital. Aims or goal of the work : Develop a standardised, evidence-based patient care pathway, Ensure good quality of services to patients and their families where treatment and care meets physical, psychosocial and existential needs, Patients and users contribute actively in the design and improvement.

**Design, methods and approach taken:** Redesign method was used to develop a coherent palliative cancer pathway based on national guidelines, together with patient representatives, multidisciplinary clinical team, general practitioners, staff and cooperating municipalities. Data was collected from hospital registers about readmission, length of stay and procedures made, next to data from the Norwegian Cause of Death Registry. Baseline measurements were also performed including audits of patient journals based on a defined set of quality indicators. A Cancer Patient Experiences Questionnaire was performed on 30 patients, together with 4 in-depth interviews with patients and relatives.

**Results:** 20 areas of improvement were identified during the redesign process and by analysing the data. Main areas to improve are: Patients receive different level of quality of treatment and care depending on cancer type / diagnosis. The organisation and treatment in the acute care department. Professional communication skills. To strengthen the offer and systematic information about support treatment integrated in the pathway. Unclear responsibility of follow-up in pain treatment. Assertive community team. Strengthen the follow-up program of relatives.

**Conclusion/lessons learned:** In palliative treatment and care it is important to develop a standardised patient-centered pathway were shared decision making and individual needs are taken into account, as this patient group will have different individual needs along their patient journey.

**Abstract number:** P1-188  
**Abstract type:** Poster

## Strengthening Patient Voices in Quality Improvement of Palliative Care Pathway in a Norwegian Hospital

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**Background:** Improvements of clinical pathways are usually not focused on user-knowledge and -experience, and are often developed by healthcare personnel. Main objective in this project was to actively use patients' and users' experiences in design and improvement of a clinical palliative cancer pathway in a public hospital.

**Aims or goal of the work:**

- Develop a standardised, evidence-based patient care pathway
- Ensure good quality of services to patients and their families where treatment and care meets physical, psychosocial and existential needs
- Implement common recommended palliative tools for measuring patient reported outcome measures
- Patients and users contribute actively in design and improvement

**Design, methods and approach taken:** The Cancer Patient Experiences Questionnaire developed by The Norwegian Knowledge Centre for the Health Service was used. 30 patients answered the survey electronically by touch-technology during their hospital visit. Additionally 4 in-depth interviews were performed to better understand patients and their relatives' needs, resulting in a movie to strengthen their voice.

**Results:** Patient response indicates patient satisfaction with the current service and important areas of improvement.

**Conclusion/lessons learned:** Ethical aspects should be taken into account when involving palliative patients in improvement projects. Still, their contribution to improve treatment and care is very important. Valuable insights are provided about the content and structure of the service, and how it is delivered. Information technology can facilitate participation in questionnaire surveys. People may have multiple roles over a lifespan, and we may all be service users at some time. By using different methods and techniques to capture users' needs and experiences the patient voice is strengthened in quality improvement.

**Abstract number:** P1-189  
**Abstract type:** Poster

## Living and Dying at Home... Not Alone: The Empowering Hold of Technology

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**Background:** Patient and family's centered Palliative Care (PC) must be organised round needs and their complexity. Our group has developed a system to answer patients and professionals' aspiration of continuity of specialist access.

**Aim:** To illustrate public and stakeholders use of the PC platform offering support, assistance, information and resources allocation. To explore reason for contacting it, prevalent diagnoses and age groups relating to patients concerned.

**Methodology:** Retrospective descriptive analysis of 4 years data related to calls received at the regional central PC platform continuously since its creation.

**Results:** Our population exceeds 6 million people; the central PC platform has established over 70000 contacts. Reasons for received calls included: resource access (including beds access) 5,78%, home death. Symptom Control- pain, dyspnea 3,64%- high fever, others (worsening condition and agitation) 3,34%. Professionals themselves established 5000 contacts to offer patient and family support and feed-back to other teams. Most frequent pathologies groups have been: respiratory 14,94%, gastrointestinal 12,85%. The most frequent coded diagnosis are lung, colon 4,2 % and pancreas carcinomas 3,6 %. 8,18-% of patients were included in the program with a non oncological diagnosis. Highest users are those between 75 and 85 years.

**Discussion:** Our patient and professional populations increasingly use this service to complement and increase care. The reasons to seek assistance are consistent with what most PC teams deal with during normal working hours. Those accessing this service are representative of all age groups and those pathologies usually requiring PC approach and intervention.

**Conclusion:** The increase in Home Care activity, community care and dying and death have come about since 24 hour PC has been implemented. Other PC professionals rely on this service to help them with patient care in all levels of care.

**Abstract number:** P1-190  
**Abstract type:** Poster

## Introducing Electronic Records in a Complex Palliative Care Service: Education of Clinical Staff

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**Background:** Our palliative care (PC) service is offering care in four locations (2 rural, 2 urban). Annually around 1800 new patients are admitted in our services (adults with cancer and children with life limiting diseases) to receive care in various settings: home care, inpatient units, day centers, outpatient clinics, lymphedema and stoma care services, hospital-through mobile teams. Communication between services is restricted due to paper held record, which is barrier especially when it comes to transfer of patients and afterhours telephone service.

**Aim:** To describe the process of educating the staff prior to the implementation of the electronic patients' records and use of mobile technologies.

**Method:** Once the funding for the project was secured we created a questionnaire for the staff to assess interests and barriers in working with electronic records and mobile devices (tablets) and the education needs in using the new technology. A curriculum was subsequently developed and rolled out including face to face training sessions with pre and post test and induction period when tablets were offered to clinical staff for getting familiar with the equipment and the potential data base.

**Results:** 107 clinical staff members out of 111, completed the survey. Based on the identified needs and barriers in using the new technology, a course with the following modules was developed:

- M1. Concepts of computer operation (135 minutes);
- M2. Skills of text editing (170 minutes);
- M3. Presentation skills (145 minutes);
- M4. Excel skills (240 minutes);
- M5. Browsing and e-mail (90 min);
- M6. Using Mobile technologies (120 minutes).

**Conclusion:** The process of educating the clinical staff in order to implement electronic patients' records was based mainly on self assessment training needs. The gradual development of knowledge and skills to work at a more advanced level with tablets and complex applications is facilitating transition toward a new digital phase of PC services management.

**Abstract number:** P1-191  
**Abstract type:** Poster

## A Cinderella Service-improving End of Life Care Provided by Domiciliary Home Care Teams in Peoples' Homes and Boosting Confidence and Competence of Staff

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**Context:** Domiciliary care workers play an important but often unrecognised role in supporting people to remain at home as they near the end of life. Despite this, few receive specific training in end of life care. Focussed training enables home care workers to improve the quality of care for such people working with primary care, and contribute to better co-ordinated cross boundary care.

**Aim:** Evaluating progress since the introduction of GSF training to Domiciliary Home Care Teams in end of life care.

**Method:** The GSF Domiciliary Care training programme in End of Life Care was introduced to Agencies across the country. The Train-the-Trainer cascade programme uses action based, interactive learning and reflective practice in 6 modules, with virtual learning Zone/DVD, and resources. Comparative before and after qualitative and quantitative evaluation is intrinsic included.

**Results:**

- Improved communication, working relationships and collaboration with District Nurses and GPs.
- Increased Advance Care Planning discussions, now part of the initial assessment plan, with information shared with others to improve coordination of care.



• Service users were keen to be involved in ACP discussions.  
• Staff showed increased confidence and felt empowered to advocate for their service users leading to improved communications with professionals  
• Increased awareness of the knowledge they already possessed and future training needs.  
**Conclusion:** This work highlights the important role that Domiciliary Care Workers play, and the importance of empowering care staff who interact with the service users on a daily basis. Use of the train-the-trainers GSF Domiciliary Care Training Programme helps to improve care for people nearing the end of life and collaboration and coordination with others. It has been well received and felt to boost the confidence and competence of Domiciliary Care Workers. Further spread is planned to reduce this being regarded as a Cinderella service in future.

**Abstract number:** P1-192  
**Abstract type:** Poster

## Better together: A Seamless Service in A Seaside Town - 15 years on

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**Background:** An area with pop. 235,000 has approximately 2,600 deaths p.a.: 500 are sudden or unexpected, 1000 known to Specialist Palliative Care Services (SPCS); 1000 predictable deaths in patients with no specialist palliative care needs. The local SPCS is integrated, and consists of NHS community and hospital teams and a voluntary hospice.  
**Aims:** An integrated service, to ensure all patients receive excellent end of life care, regardless of diagnosis, place of care or whether they are known to the SPCS.  
**Method:** An integrated SPCS acts as the central hub for supporting all who care for patients approaching end of life. Collaborative working with primary and secondary care and care homes, with support of trust executive board, hospice board of trustees and clinical commissioning groups (CCG) enables use of common processes and shared documentation. In addition to 7 day SPCS supporting all healthcare settings, with strong clinical relationships, a 7 day a week designated education and support team, working out of a hospice education centre, enables all health care professionals to access training appropriate to their role wherever they work. An active End of Life Strategy Steering Group brings together influential individuals from hospital and community to drive change within the organisation and a local SPCS group brings these together with hospice and CCG staff. Active, cross boundary audit programmes highlight need and are a springboard for change and development in all areas. Incidents and failures of co-ordination are discussed and analysed to form the substrate of change.  
**Results:** For 3 consecutive years deaths, from all causes, in usual place of residence have exceeded hospital deaths and are doing so increasingly enabling majority to achieve preferred place of care.  
**Conclusion:** Collaborative working has led to a swell of enthusiasm which engulfs all staff in all local healthcare organisations, changes culture and helps recognition that end of life care is everyone's business.

**Abstract number:** P1-193  
**Abstract type:** Poster

## Differences in Palliative Care Delivery Confirmed in a European Prospective Study - (EPCCS) - Consequences for Palliative Care Research

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**Background:** Palliative care (PC) is organised differently across countries. This may indicate suboptimal PC organisation, may hamper generalisability of study results, and calls for high quality research to identify who the PC patients are in relation to organisational and medical variables.  
**Aims:** To describe the organisation of PC at participating sites including characterisation of PC patients on sociodemographic and medical data.  
**Methods:** A web-based centre survey on organisation, economic and academic resources was completed prior to patient inclusion. Patients were recruited at initiation of, or during PC treatment. Symptoms were self-reported at inclusion and every 4 weeks for 3 months/until death (up to 11 months at some sites). Medical data were registered by medical staff concurrently, on web or paper.  
**Results:** 30 centres; 19 hospitals, 1 nursing home, 3 hospices, 1 home service in 12 countries took part. 73% had PC hospital teams and in- and outpatient services, offering chemo/radiotherapy. Annual no. of PC patients ranged from 113-729. Appr. 90% had cancer. Mean length of patient stay ranged from 7-73 days. Physicians/nurses were present 24h/7d in 49% and 63% of centres respectively. 14 centres had ≥ 1 medical professors, 3 had ≥ 1 professors in nursing. 12 centres had full/part-time research staff. State and/or community funding was predominant (86%). 1739 (8-150 per site) patients were included; M/F: 50/50, median age 66 (21-97), median Karnofsky score 70 (10-100). Lung and GI-cancers were common >50%, >80% had metastases, 41% received chemo upon inclusion. 1066 patients died during follow-up; mean survival was 157 days (SD 152) from inclusion.  
**Conclusion:** Variations in PC organisation, resources, delivery, treatment and patient mix were revealed. The extent of integration of PC and oncology varied. Thus, studies in PC must employ strict inclusion criteria to ensure a uniform characterisation of patients that permits generalisability of results.

**Abstract number:** P1-194  
**Abstract type:** Poster

## A Scoping Review to Explore the Feasibility of Establishing a Care Home Centre of Excellence, Innovation, Training and Research in Scotland, UK

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**Background:** The increasing demographics of the oldest old in European societies and the demand for quality care towards the end of life is putting pressure on health/social care policies and long-term care institutions to think strategically. In the UK, the majority of residents admitted to a nursing care home die within a year of admission. There are three times the number of care home beds than in the NHS; however, little undergraduate training and education is undertaken in these institutions. Rarely do professionals seek a career in the care of frail older people in care homes.  
**Aim:** To undertake a scoping review of teaching nursing homes (TNHs) and to work with local universities, health and social care to establish plans for a care home centre of excellence, innovation, training and research.  
**Methods:** A scoping review methodology was adopted because of the lack of research literature to undertake a formal systematic review. Available academic literature, grey literature and websites were examined using the term teaching nursing home (TNH). Telephone interviews and meetings were held with key stakeholders in Scotland, Norway and Holland. Data were selected, sorted and categorised in relation to funding, training, innovation and research.  
**Results:** An initial report on 26 studies was written. Despite TNHs serving frail older people, there was no reference to end-of-life care or palliative care training. Benefits and challenges associated with TNHs were highlighted and resources required to establish such an innovation. The systematic process of developing a TNH enabled health and social care, and, geriatrics and palliative care and funders to work together.  
**Conclusion:** The education of care home staff in the care of frail older people in the last year of life alongside undergraduate education and training at a TNH has the potential to raise the profile of aged care workforce and promote recruitment into this neglected area of care.

**Abstract number:** P1-195  
**Abstract type:** Poster

## Memory First - A Primary Care Based Holistic Service

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The aim of the Memory First service was to scale up a memory service from a single pilot GP practice to 41 practices across two commissioning localities. The new partnership between a local GP Federation and two hospices aims to deliver a holistic service, tackle unmet need and improve EOLC for people with dementia. A standardised service design was implemented across all practices. A key role in the service delivery is the new role of a non-clinical Care Facilitator (CF). The hospices employ, train and manage the CF element of the service. The CFs have an honorary contract with allocated GP Practices enabling them to access/update records as part of the primary care team. The CF undertakes a holistic assessment and conducts the General Practitioner Assessment of Cognition (GPCOG). The CF decides whether to book the patient into a memory clinic which is held in primary care and/or signposts, organises other services to meet needs from the assessment such as falls, social care, carer support, social groups etc.  
Since January 2014 to end of August 2014, 1273 patients have been referred to the service, 859 have received a holistic assessment by a hospice employed CF. 37% have required attendance at a memory clinic for diagnosis, of the patients who have completed the pathway just under 50% of patients attending clinic receive a formal diagnosis of dementia.

Key Performance Indicators	Average for all patients
KPI 1 GP referral to first Standard Structured Assessment - 95% within 10 weeks (50 working days)	31.7 working days
KPI 2 GP referral to memory clinic - 95% within 50 working days	65.5 working days*
KPI 3 GP referral to diagnosis - 95% within 15 weeks (70 working days)	68.8 working days

[KPI]

\*One of the key lessons in the roll out of the service is the comparison of numbers of patients seen in clinic in comparison to the initial single practice. This issue is being evaluated as part of the on-going review of the service.  
Results from patient and family reported outcome measures demonstrate high satisfaction in the service. Many patients citing increased feeling of reassurance and support.

**Abstract number:** P1-196  
**Abstract type:** Poster

## Talking Integrated Palliative Care: What Should We Be Talking about?

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**Objective:** The FP7 project InSup-C aims to determine the best way to deliver integrated care to people who have advanced cancer, heart or lung failure at the end of life. The wide range of services available leads to questions about which organisational requirements an integrated palliative care service should meet and how integration should be achieved.  
**Methods:** An online questionnaire was sent to 10,848 EAPC contacts. 665 responses were received and statistically analysed with SPSS.  
**Results:** An IPC approach should involve at least two different organisations (63%) and cover both homecare and inpatient settings. Most participants chose a network approach based on familiarity with, and approachability of, palliative care specialists (70.2%) over a

formalised structure based on designed roles and procedures (26.3%). The most preferred organisational structure was a specialist or palliative care team with an advisory function (45.6%) followed by the option of an integrated team with a single joint treatment plan (32.9%) and a loose network of specialists and generalists (17.3%). The top three methods selected to integrate palliative care are: training and education (95%), guidelines/pathways (85%), standards/protocols (77%). The service should be accessed via referral by a medical professional rather than patient self referral (GP 91%, specialist 89%, patient 60%). The service should be available 24 hours a day according to 68% or provide an out of hours service in addition to the integrated palliative care service (27.4%).

**Conclusions:** Optimal patient centred IPC approaches are characterised by high availability and flexibility. The data show a clear tendency towards a network approach which builds on familiarity and accessibility.

The research leading to these results has received funding from the European Union's Seventh Framework Programme (FP7/2007-2013) under grant agreement n° 335555

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**Abstract type:** Poster

## Integrated Palliative Care in Cancer, COPD and Heart Failure: What Is the Optimal Timing?

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**Objective:** Early integration of palliative care (PC) is a contentious topic, as is the integration of PC in different disease trajectories. Developing patient centred integrated PC (IPC) approaches in cancer, chronic obstructive pulmonary disease (COPD) and heart failure (HF) demands more information on disease specific requirements.

**Methods:** An online questionnaire was sent to 10,848 EAPC contacts. 665 responses were received and statistically analysed with SPSS.

**Results:** According to the participants information on PC should be given later in COPD/HF (Gold Standard 3: 43.3%/NY HFC: 3 48.6) than in cancer (time of diagnosis: 61.3%). The same disease stages are suggested by a majority (>50%) as the starting point of PC consultation in COPD/HF. In cancer there was no majority in favour as to when PC consultation should start. In all disease groups respondents suggested that treatment should be taken over by PC teams at a later stage (advanced cancer: 54.7%, Gold Standard 4: 48%, NY HFC 3: 50.3%). The majority chose the GP as primary contact person for COPD/HF patients (43%) and in cancer (35.9%). In cancer the significance of the PC specialist (14.9%) is considered higher than in COPD/HF (8%/7.5%). Responsibility for PC treatment in all disease groups is seen as that of the PC specialist (cancer: 58%, COPD: 46.1%, HF: 46.2%). Most respondents favoured PC specialists as the lead clinician in cancer (homecare 22.3%, inpatient 33.5%) than in COPD/HF (homecare 13.6%/14.3%, inpatient 23.9%/24.6%).

**Conclusions:** Our findings suggest similar requirements for IPC in COPD and HF, but that these differ from those in cancer. Different requirements in terms of timing of the introduction of PC and with whom key responsibilities lie, need to be considered in the development of IPC approaches in different conditions.

The research leading to these results has received funding from the European Union's Seventh Framework Programme (FP7/2007-2013) under grant agreement n° 335555

**Abstract number:** P1-198

**Abstract type:** Poster

## Research Active Hospice-moving Forward

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**Aim/Goal:** The Help the Hospices report 'Research in palliative care: can hospices afford not to be involved?' highlights the need for hospices to strengthen their contribution to research and the evidence behind the interventions they offer. A Hospice in Scotland was inspired by the report and has adapted the 3 level research framework to become a 'Research Active Hospice'.

**Method:**

Multidisciplinary steering committee for research was established within the Hospice to take this work forward.

Three level framework was used to map out current research activities, identify gaps and inform research strategy.

Senior staff with background in research have dedicated time for research

Frontline staff being encouraged to enhance their research skills through the provision of a series of short workshops addressing general skills

Formal link made with academic research teams who focus on palliative and end of life care issues, in 3 local Universities

Regular meetings, open to all clinical staff, providing a forum to discuss new ideas, new proposals and ongoing work

A writing group meets every six weeks to support those writing for publication, presentation or degree thesis

**Results:** Adapting the framework in the Hospice has increased the research capacity and enabled more focused approach for research activities.

The collaboration with established research teams in Universities allows for a more rigorous approach to investigating and developing practice, sharing of ideas and developing research proposals together.

**Conclusion:** The report from Help the Hospices has supported the Hospice to move forward in making research more established, accepted and expected within the Hospice.

**Abstract number:** P1-199

**Abstract type:** Poster

## Do We Need a Network Coordinator for Liverpool Care Pathway in Norway? An Evaluation Study

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**Background:** Liverpool Care Pathway (LCP) was introduced in Norway in 2007 and has since been implemented at 339 (Oct 2014) sites across the country. The increasing number of user sites created a demand for coordination and quality assurance. In 2012 we set up a position for a network coordinator for LCP as a two year project. The coordinator is available for advice, audit, and teaching.

**Aim:** To evaluate the function of the network coordinator and the need for this position.

**Methods:** A web-based survey was developed using SurveyMonkey and sent to all LCP main contacts in Norway in September 2014 (n=233), with two reminders. (We also performed qualitative interviews in a representative sample, but results from the interviews will not be presented here.)

**Results:** We received at total of 154 (66.1%) responses: 111 nursing homes, 38 municipal home care services, 15 hospitals and 9 other. 33% had been using the LCP less than one year, 44% 1-3 years, and 14% more than 3 years; the rest were in the process of implementing the care pathway. The majority considered all elements of the 'start kit' 'very useful' or 'useful', especially the algorithms (93.1%), information leaflet (91.5%), and guidance for local LCP lead (89.3%). 57.7% had attended a regional LCP conference. 86.4% were aware of the network coordinator and 71.7% had been in contact with her, mostly by E-mail; 79.8% rated her availability as very good. The most common reasons for contacting the coordinator were questions regarding registration, implementation, education, and practical use. The respondents clearly saw a need to continue the position of network coordinator (57.7% 'high' and 33.7% 'moderate need'). Many respondents gave free comments describing the usefulness of having a national coordinator.

**Conclusion:** The results of the survey show a positive evaluation of the LCP network coordinator function and a continued need for this position.

**Main source of funding:** The Norwegian Directorate of Health

**Abstract number:** P1-200

**Abstract type:** Poster

## Realist Evaluation of a UK Specialist Care at Home Innovation

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The Macmillan Specialist Care at Home service is designed to bring together teams of professionals who work in an integrated way to improve palliative and end of life care for people affected by cancer and attendant chronic conditions, in the community. Some of the outcomes it is designed to deliver are associated with less frequent Accident and Emergency admissions, reduced stays in hospital and a majority of people being cared for and dying in their preferred place. The proposed evaluation utilising a realist evaluation model; 2 year evaluation commenced May 2014; of six innovation sites is designed to build capacity with regard to self-evaluation: to integrate and embed sustainable evaluative processes into the Innovation Centres from the start. This will include the development of evaluation tools to be refined and shared with the Centres. A key aspect of the evaluation will be to develop good communication channels with the Innovation Centres to facilitate and support building capacity for robust but pragmatic evaluation practices at local levels. The realist evaluation will answer the questions: 'What works, for whom, in what respects, to what extent, in what contexts, and how? The underlying generative mechanisms that explain 'how' the outcomes were caused and the influence of context will be identified. Data will therefore be collected using a mixed methods longitudinal approach involving three main elements: Evaluation participatory training workshops; Case studies of the six Innovation Centres; National stakeholder enquiry. Data will be collected on context, process and outcomes utilising a specifically developed service data tool as well as reliable and valid outcome measures and qualitative observation and interviews.

**Abstract number:** P1-201

**Abstract type:** Poster

## Straight to the Point: A Week in the Life of Point of Care Hospice Ultrasound

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**Background:** The literature shows increasing use of ultrasound within the hospice setting. Our hospice has been using point of care portable ultrasound scanning (USS) to enhance patient care, by answering a specific clinical question, since 2010. We feel USS has transformed the patient experience since its introduction to the service. Previously presented data from Dec 2010 to Mar 2014 shows that 158 patients had 286 scanning episodes resulting in 164 procedures. The perception is that USS use continues to increase.

**Aim:** To ensure that the use of USS within hospice use is to answer specific clinical questions and to assess frequency of use within a single week.

**Method:** Retrospective snapshot review of one week of point of care ultrasound in a ten bedded hospice setting. Patients and scanning episodes identified by a search of memory on ultrasound machine and corresponding entry on electronic clinical record.

**Results:** During this week there were 12 separate scanning episodes (3 inpatient and 4 outpatients) by 3 doctors resulting in 8 procedures. Each answered a clinical question - Is urinary retention present? (2 patients: 1 procedure); Is there a drainable pleural effusion? (2 patients: 2 procedures); Is there drainable ascites? (3 patients: 2 procedures); Location of peripheral nerve for nerve block (1 patient: 3 procedures).

**Conclusion:** This snapshot audit confirms that point of care USS is being used extensively within the hospice as part of the clinical examination alongside the stethoscope. It is being used appropriately to answer specific clinical questions, leading to decreased admission to intervention time and hence faster symptom relief with less upheaval for patients. USS enables the hospice to provide a responsive service, to arrange planned admission for increasingly symptomatic patients allowing for necessary blood tests and investigations prior to admission. Data for the year 2014/15 will be available for the conference presentation.

**Abstract number:** P1-202  
**Abstract type:** Poster

## The State of Social Palliation in Denmark

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EAPC has published White Papers in 2013 on education for the care of palliative patients and established a task force of social workers. In Denmark, a group of social workers in specialised palliative care is building on this to upgrade psychosocial support and intervention. Social Palliation focuses on legal options and psychosocial support during terminal illness and in the aftermath of death. It draws on five areas: Theories and methods in Social Work, Legal aspects, Psycho-social issues, Social Science and Environmental Health. **Key activities**

We have conducted a study in two specialised palliative teams in larger Copenhagen, covering 286 patients over a period of 14 months. The study focuses on patients' social need of support and reveals the relevance of addressing social aspects of terminal illness, as the majority express such needs.

Standardised curriculums for palliative care professionals are prepared by the Danish Multidisciplinary Cancer Group in Palliation. Within this framework, we have developed 'National Recommendations for Competences of Social Workers in Palliative Care', as prior no qualifying curriculum existed for social palliation.

### Achievements

- Completion of a quantitative and qualitative study demonstrating the need for support in psycho-socio-legal matters in palliative care
- Development of a training program for social workers
- Established liaison to educational institutes and municipalities
- Published article on the need for social palliation, Omsorg 3/2014
- Initiating a professional association for social care

Our work provides a framework for expanding the knowledge of social work in specialised Palliative Care. It gives options for screening, optimising the focus of work and calls for the coordinating and bridging role between the specialised level and the basic level in primary care. Social palliation works towards relieving family distress and securing their rights.

**Abstract number:** P1-203  
**Abstract type:** Poster

## Development of Palliative Care Nursing Specialization in Poland

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Nursing in Poland has changed over the years, as well as regulations and conditions of nursing profession. The first law regulating the legal status of nurses and rules of the profession comes from 1935. Further legislation expanded competences and independence of professional nurses. On the basis of the regulation of the Minister of Health and Social Welfare of 17 December 1998, in the course of two-year post-graduate studies ending with a state exam nurses can obtain the title of specialist in the field of palliative care nursing. However, the draft of a new list of specialisation in 2011 did not include palliative care nursing. On 12 December 2013 the Minister of Health signed a decree on the list of fields of nursing and disciplines applicable to health care in which specialisation and qualification courses can be carried. On this list, among thirteen areas, palliative care nursing have been included. Implementation of certain benefits by a nurse without a doctor's order is subject to the holding of a specialist course or obtaining a nurse specialist title. On 12 August this year, President of the Republic of Poland signed an amendment to the Act on professions of nurse and midwife to grant nurses and midwives power to 'ordain medicines and to issue prescription for medication'. Since 2006, Polish Society of Palliative Care Nursing associates more than three hundred active professional nurses. Currently in Poland, almost 4000 nurses implement the provision of palliative and hospice care. 649 of those nurses obtained specialisation in the field of palliative care nursing. A particularly important element in the maintenance of the specialisation was the decision of the Minister of Health of 20 December 2011 on the appointment of the National Consultant in the field of palliative care nursing.

**Abstract number:** P1-204  
**Abstract type:** Poster

## Cancer Patients Dying in Intensive Care Unit (ICU) is it Avoidable?

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The ICU doesn't seem to be the best place for dying patients with cancer, but in a previous study we found out that 42 (16) patients out of 536 cancer patients died in ICU in our university hospital in 2010.

**Goal:** We would like to explore the characteristics of the patients and to find out if the referral to the ICU could be avoidable.

**Methodology:** We reviewed the patients' charts for: the demographic data, the cancer site and metastatic status, chemotherapy undergone, and the main cause of the referral. We also studied the access to Palliative care service, and the patient preference about the end of life issues.

**Results:** 42 cancer patients died in ICU in 2010. 62% were male, age 68 (16); the most frequent cancer types were hematologic (21%), gastrointestinal (21%) and head and neck (21%). 36% had metastatic disease. The mean length of stay was (14 days (SD; 13) in ICU. Only one patient had access to a palliative care service (vs 45% in cancer patients population who died in other departments, p< 0,001), and that was during the last day. 24% of the

patients received two chemotherapy lines or more and 19% during the last month of life, two of them during the ICU stay. The main cause for referral in ICU was septic choc (14(33%)) and acute respiratory distress (12 (29%)). 74% of ICU referral are linked with the cancer disease. Decision to withdraw life-support measures was taken for 76% patients and death occurred 2,2 (3) days after that decision. No proxy or patients preferences was found in the patients' charts.

**Conclusion:** The collaboration with the oncologist and hematologist should start earlier. We assume that opening a discussion with the patient and his family about the end of life issues could avoid the unnecessary referral in ICU.

**Abstract number:** P1-205  
**Abstract type:** Poster

## Refining the GP Out-of-Hours (OOH) Palliative Care Handover Form

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**Background:** A project commenced in 2012 with an OOH service to develop a palliative care information transfer process. A GP à OOH Palliative Care handover form was developed and pre-piloted in 2013. After the pre-pilot phase the form was redesigned and condensed from 3 pages to 1 page. A guidance document and information leaflet was developed to support implementation of the form in one geographical area.

**Aims:** This work aims to report on an evaluation of the implementation and use of the form and identify necessity and relevance of the tool within other healthcare settings.

**Methods:** A mixed methods approach was used. Quantitative data from forms received was gathered and a series of qualitative interviews were carried out with GPs and nurses who used the form and with healthcare workers in residential centres and members of the specialist palliative care community who hadn't used the form. Interviews were recorded and data analysed for key themes.

**Results:** Early findings indicate that:

- Those that had used the form identified that it supports the transfer of relevant information from GPs to OOH services to assist in the care of patients with palliative care needs.
- Within other healthcare settings the forms adds to existing paperwork.
- Use of such a form has the potential to enhance information transfer and service delivery within other healthcare settings.
- The use of a shorter form appears to increase the likelihood of form field completion.

**Conclusion:** Accurate transfer of information to OOH services enhances delivery of care and assists in the decision making process of practitioners. Use of such a form has the potential to enhance residential and specialist palliative care services and integration of key fields where existing paper work exists.

**Abstract number:** P1-206  
**Abstract type:** Poster

## Burden of Emergency Medical Service with Palliative Home Visits in Slovenia

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**Introduction:** Palliative care (PC) in Slovenia is a developing medical profession. Today, the majority of PC patients in Slovenia are under medical treatment by family doctors. Out of their working hours PC patients with an acute deterioration of symptoms are taken care by the emergency medical service (EMS), which represents additional work load to the emergency teams.

**Aim:** To determine the burden of EMS with PC home visits in different region of Slovenia. The analysis included three units of EMS, which differ in composition.

**Methods:** Data were collected through a questionnaire during a 3-month period. Data were analysed with methods of descriptive and analytic statistic.

**Results:** The results are shown by regions respectively by units of EMS. In pre hospital unit Ljubljana 20% of all house visits (HV) were due to PC calls. Emergency interventions were recorded in 2,3 %. The most common problem was dyspnea (27 %). Out of all, 15 % of patients had been transferred to hospital. In the Unit 1B ZD Gornja Radgona there were 15,8 % palliative HV. The most common cause for the phone call was uncontrolled pain (33 %). 37 % of patients had been transferred to hospital. In the Unit 1A ZD Vrhnika 14 % of all HV were palliative. Dyspnea was the most common cause for the call (32 %). 27 % of patients had been sent to the hospital.

**Conclusion:** Load of emergency home visits due to PC acute complication has ranged from 14% to 20%. In smaller units there were less palliative HV, which can be explained by the fact that emergency doctor in rural areas are more familiar with PC patients. In two EMS units the most common cause of palliative HV was dyspnea, following by pain. In rural areas percentage of referrals to hospital was higher, most probably due to smaller set of investigations, which are available at home setting in those EMS. In a future, PC in Slovenia could be improved with the formation of mobile palliative teams that could intervene in such palliative crisis.



**Abstract number:** P1-207

**Abstract type:** Poster

## GPs' Participation in Multidisciplinary Oncology Consultations Interview Study in Belgium

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**Background:** Multidisciplinary Oncology Consultations (MOC) allow health care professionals to meet, discuss and achieve shared goals in cancer patients' care. In Belgium, MOCs have been reimbursed since 2003 by the National Institute for Health and Disability Insurance (NIHD). Though the legal framework recognises the importance of GP's participation in the MOC, it is not mandatory. Furthermore it does not provide any task description. Currently GP's participation is minimal. Little is known what the perceived barriers for participation are and how Belgian GPs perceive their role toward MOC participation.

**Aim:** This study aims to describe GP's perceived roles toward the MOC, the GP's expectations and barriers for participation to the MOC.

**Methods:** Semi-structured interviews with 16 GPs throughout the country, all having MOC experience. Data-saturation is reached. Thematic analysis principles are used to analyse data. **Results:** GPs consider MOC participation as a part of their job and are willing to make efforts to attend the MOC meetings. Their perceived roles at the MOC depend on the complexity of the patient's case, the quality of the interactions with other participants and task agreements with medical specialists. Current experiences depend on practical factors (eg. timing and quality of the invitation, timing of the MOC during the day, proximity of the hospital), interpersonal factors (eg. quality of the relationship with the specialists) and the educational aspect of the MOC. An important motivator to participate is the GP's perceived added value to the MOC discussion.

**Discussion and conclusion:** GPs confirm the necessity of effective collaboration with specialists in the complex situation of cancer patients' care. A MOC is an operationalisation of inter-professional care and fosters interpersonal contacts with specialists, eventually leading to better patient care. Most barriers for attendance are practical, which may be overcome through video-conferencing.

**Abstract number:** P1-208

**Abstract type:** Poster

## Implementing a Manualised Integrated Palliative Care Model for Care Home Residents with Advanced Dementia

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**Background:** The number of people living and dying with dementia is increasing. Evidence suggests that people with advanced dementia may receive poorer quality end of life care including aggressive treatments and failure to manage pain and distress.

**Aim:** To explore the feasibility and benefits of a manualised integrated care model for improving palliative care for care home residents with advanced dementia.

**Method:** A mixed methods realistic framework was used to develop the intervention. An advanced dementia interdisciplinary care leader (ICL) implemented the manual in two care homes over six months. The ICL undertook holistic assessments of 30 residents, liaised with family members, care home staff, external health professionals and conducted training sessions for staff. Evaluation involved collection of outcomes including place of death, number of residents with pain management plans and recorded resuscitation status. The ICL maintained a reflective diary and interviews were conducted with care home staff, professionals and family carers to explore barriers and enablers to implementation, observations of practice change and care home dynamics.

**Results:** The ICL identified areas for improved care, including pain management, documentation and referral to other health professionals for individual residents. Sessions for family members on dementia and end of life care and for staff on agitation during bathing and pain and behavioural symptoms were positively received. The nature of this complex intervention enabled the ICL to adapt the role to address different issues in each care home context. Outcomes, barriers and enablers will be reported.

**Conclusion:** This feasibility study shows promising findings in improving the quality of care for care home residents with advanced dementia and highlights areas for refining this manual and model of care.

This programme was funded by Marie Curie Cancer Care through a process administered in partnership with Cancer Research UK.

**Abstract number:** P1-209

**Abstract type:** Poster

## Developing Basic Palliative Care in the Community: Consensus Meeting

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**Background:** The Romanian Palliative care (PC) strategy proposal defines 3 levels of care according to complexity of needs: selfcare; basic PC; specialised PC. Funding was secured through a Romanian Swiss partnership project to develop a model of basic PC interventions for cancer patients in the community and to pilot it through GPs in 4 districts in Romania.

**Aim:** To describe the process of developing the model of basic PC interventions for cancer patients in the community.

**Method:** Initial qualitative research (case studies, focus groups) was run to identify needs, gaps and barriers in care of cancer patients in community followed by national survey to test the results. Research results were presented to Romanian and Swiss experts (legal, financial, organisational, education) who made recommendations for the basic PC model. The draft model was refined in a 2 day consensus meeting with various stakeholders and an action plan for implementation was established.

**Results:** 38 stakeholders attended the meeting (GPs, Nurses, representatives house of insurance, college of doctors, oncologist, PC home care service providers, Associations of GPs, UK and Swiss experts). Agenda included: international models for basic PC in community, research results, group work to discuss the interventions, the instruments to be used and solutions for overcoming barriers in implementation. Following interventions were agreed: assessment (needs using ESAS and KIPCC, family capability, complexity of case), symptom management (protocols for 9 symptoms on ESAS), communication (algorithm collusion, breaking bad news, negotiation goals of care), terminal care (protocol), care coordination (documentation). Initial education (40 hours), monthly case reviews with local PC specialist, support helpline were seen as integral part of the model. Workgroups were defined to lead various activities (recruitment GPs, costing, monitor outcome, ...)

**Conclusion:** Great interest and support for the initiative is encouraging.

**Abstract number:** P1-210

**Abstract type:** Poster

## Contacts to a Doctor-led Out-of-Hours Telephone Service for Specialist Palliative Care in a Danish Region

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**Background:** In September 2013, Central Denmark Region (approx. 1.2 million inhabitants) established a new doctor-led out-of-hours telephone service for specialist palliative care performed by consultants from five outreaching palliative care specialist teams (PCST). Contacts were made by general practitioners (GPs) on call, hospital doctors, hospice nurses from four hospices and primary care nurses concerning patients in PCST care. The service was open from 3pm to 8am on weekdays and 24/7 on weekends/public holidays.

**Aim:** To describe nature of contacts within the first year to a newly established doctor-led out-of-hours telephone service for specialist palliative care.

**Method:** Contacts to the service from 1 September 2013 to 31 August 2014 were registered using a pre-defined form. Descriptive analyses were performed concerning contacting institution and the reason for contacting the service using STATA 13.

**Results:** The service was contacted 737 times (mean: 2 contacts/day (range: 0;12)) with an increasing number of contacts with time; Mean was 2.4 contacts/day during the last six months of the one-year study period. The contacting professionals were hospice nurses (71%), hospital doctors (15%), primary care nurses (8%), GPs on call (3%); irrelevant contacts constituted 3%. The most common reasons for contact were pain (34 %), delirium (13%), infection (8%), dyspnoea (6%), medication problems (5%), nausea/vomiting (3%), patients too ill to take oral medication (3%), malignant bowel obstruction (2%), anxiety/depression (2%) and lethargy (2%); 92.2 % of contacts concerned patients with cancer.

**Conclusion:** Contacts were most often made by hospice staff and the most common reason for contact was pain. Number of contacts showed an increasing tendency during the first year thus indicating that a 24/7 specialist service is important to ensure optimal palliative care. Further documentation and evaluation of future out-of-hours palliative care services is warranted.

**Abstract number:** P1-211

**Abstract type:** Poster

## Associations between Contacting Professional and Contact Reason in an out-of-Hours Telephone Advice Service for Palliative Care in a Danish Region

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**Background:** Around the clock availability is a cornerstone in palliative care. General practitioners (GPs), primary care nurses, hospital doctors and hospice nurses have previously not been able to obtain specialist palliative care advice out-of-hours. In September 2013, Central Region DK (approx. 1.2 million inhabitants) established a doctor-led out-of-hours telephone advice service for specialist palliative care. Our hypotheses were that pain and problems among cancer patients cancer were more frequent reasons for contact among non-specialised professionals than hospice nurses, since non-specialists tend to believe palliative care is merely concerned with pain and cancer.

**Aim:** To analyse if problems and diagnoses leading to contacts with a doctor-led out-of-hours telephone advice service were associated with the contacting institution.

**Method:** Contacts from 1 September 2013 to 31 August 2014 were registered. Contact reasons were dichotomised into pain/non-pain, diagnosis into cancer/non-cancer and contacting institutions into hospice/non-hospice. Regression analyses were performed.

**Results:** We found a significantly higher risk of reason for contact being pain with non-hospice institutions (PR=2.27(p: 0.00)). The same significant difference was found between nurse-led hospice-contacts and primary care nurse contacts indicating that the difference is more pronounced between specialised and non-specialised institutions than between professions. A total of 92.2 % of contacts concerned patients with cancer, but we found no significant differences between diagnosis and contacting institution (RR=0.98 (p: 0.50)).

**Conclusion:** Contacts from non-hospice institutions significantly more often concerned pain; the same difference was not found concerning cancer. Results suggest a need to communicate that the service may be used for other purposes than pain among professionals from non-specialised institutions and in other patient groups than patients with cancer in general.



**Abstract number:** P1-212

**Abstract type:** Poster

## Adapting the Dignity Care Intervention to a Swedish Context

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**Aims:** The Dignity Care Intervention (DCI) was developed in Scotland to be used by community nurses caring for patients with palliative care needs, with an aim to conserve patients' sense of dignity. The DCI includes the Patient Dignity Inventory (PDI) that is used to identify dignity related concerns. In a dialogue with the patient, the nurse discuss identified concerns and ways to address them by using reflective questions and evidence based care actions provided in the DCI. The DCI is now translated and adapted for implementation in Swedish palliative care.

**Design, method, and approach:** DCI is based on Chochinov's model of dignity and the PDI is one key component. Two researchers independently translated the model and the inventory from English to Swedish and the research group examined the translations together with the original versions. An expert review focusing on items and response alternatives was accomplished followed by cognitive interviews with patients answering the preliminary Swedish version of the PDI. Evidence based care actions were updated with Swedish publications such as theses, clinical guidelines and governmental publications.

**Results:** Swedish versions of the model of dignity and the PDI were produced, the process of translation and adaptation added clarity and consistency. From the review of Swedish publications, care actions were adapted and updated.

**Conclusions:** The focus has been on achieving cultural relevance which might have affected equivalence to the original model of dignity and the PDI. To get local context evidence for care actions, focus group interviews will be conducted with nurses, physicians, patients and family members. After the process of adapting the DCI it will be implemented and evaluated in clinical settings. Two clinical settings have agreed to collaborate in this phase. Implementing the culturally adapted DCI will be a way for nurses to provide evidence based and person centred palliative care.

**Abstract number:** P1-213

**Abstract type:** Poster

## Profiles of Palliative Care Services and Teams Composition in Brazil: First Steps to the Brazilian Atlas of Palliative Care

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The population ageing and health professionals growing interest culminated in the revision of several Brazilian regulations, improving population access to Palliative Care services since the years 2000. To have a better understanding of practices and integrate the services, two encounters were organised (2012/2014) by a company called MAIS Group, which is developing the Brazilian Atlas of Palliative Care.

**Aim:** To characterise the profile of palliative care services in Brazil.

**Method:** Services, included on the electronic mailing lists from the National Academy of Palliative Care and the MAIS Group, were invited to participate of a free of charge online survey. State; funding structure; type of service; team composition; palliative care training; dedication and teamwork functioning were asked.

**Results:** 68 services (from 16 Brazilian states) answered; 35 are located in São Paulo State. The most prevalent model is ambulatory (53%/36); mixed population (57%/39), assistance to adults (88%/60) and elderly (84%/57) prevails, and public funding (50%/34) prevail. Services reported team composition: physicians (98.5%/97), nurses (98.5%/97), psychologists (92.6%/63), social workers (92.6%/63), physiotherapists (80.9%/55), speech therapists (70.6%/48), spiritual assistants (61.8%/42), pharmacists (64.7%/44), occupational therapists (53%/36), dentists (51.5%/35), and volunteers (40.6%/26). The major part were reported as part-time workers with little or non-specific formation. 89% (60) have clinical meetings and 68% (46) of those indicated weekly meetings.

**Conclusion:** It's worrisome that there is a marked concentration of services in only one State, that the majority of them assist adult/elderly with no trained professionals in Palliative Care. This study is not without limitations; there is a possibility that sample does not include all palliative care services in the country, however this study provides useful insight regarding the development of Palliative Care in Brazil.

**Abstract number:** P1-214

**Abstract type:** Poster

## Specialized Outpatient Palliative Care - Results from a Representative Survey among Physicians in Germany

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**Background:** Specialised outpatient palliative care (SAPV) since 2007 allows patients (pts) with incurable diseases and limited life expectancy to be cared for until death in their familiar surroundings. Little is known about structure, organisation and work pattern within SAPV teams.

**Methods:** An online survey was carried out from 9/2013 to 3/2014 with 124 physicians with aspects related to qualification, networks and palliative care teams. Aim of survey was to evaluate the status quo of SAPV from the viewpoint of physicians.

**Results:** 120 respondents (96.77%) were enrolled in SAPV; 18.33% of them (n=22) were on a direct contract with a health insurance provider. An additional qualification for palliative medicine and for pain therapy was reported by 96.69% and 21.49% of the physicians, respectively. In average, 11.62% are organised in a network. The networks comprise GP's (in 88.60% of the networks), anesthesiologists (in 62.28%), hematologists/oncologists (in 57.89%) and internists (in 43.86%) as well as a large proportion of non-medical professions. Mostly, SAPV networks are linked to one or more medical practices, hospitals or welfare

institutions. 96% assessed the cooperation within the network as 'very good'/'good'. Pts admitted to SAPV were mostly suffering from cancer, but also from cardiovascular, neurological and respiratory diseases. Mean duration of care was 26.63 days; 81.43% could die in familiar domestic surroundings. On average, one physician is treating 9.66 SAPV-pts at the same time. Documentation requires 25.86% of time spent for medical care. Problems concerning reimbursement were reported by 75.80% of respondents.

**Conclusions:** The survey provides the status quo of the German SAPV concept. Physicians enrolled in SAPV are highly qualified for palliative care and pain therapy. SAPV is the domain of the outpatient care sector. While interdisciplinary cooperation within the SAPV networks is good, documentation and reimbursement remains a problem.

**Abstract number:** P1-215

**Abstract type:** Poster

## The Cooperation between Physicians and Pharmacists at Polish Residential Hospices

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**Background:** In hospice and palliative care pharmacists together with the other medical staff are involved in supporting patients in dealing with pain and other symptoms related to life-threatening illness.

**Aims:** The aim of the study was to evaluate the physician-pharmacist cooperation at Polish residential hospices.

**Methods:** A cross sectional survey was applied. Two types of anonymous questionnaires were addressed to physicians and pharmacists from all Polish residential hospices (n=93). The questionnaires were consisted of 2 types of questions: closed ended with a tick box categories and open ended. Statistical analysis were calculated using STATISTICA Version 10.

**Results:** 16 pharmacists and 30 physicians from 32 hospices responded to the survey (response rate 34%). 19 out of 32 residential hospices cooperate with the pharmacists. Both pharmacists and physicians stated that the pharmacist is not a member of palliative care therapeutic team, however he should be. The study indicated that pharmacists more often cooperate with nurses than with physicians. Nevertheless, physicians reported that their cooperation with the pharmacists involve: advising them in pharmacotherapy (27%), monitoring of adverse drug reactions (20%), compounding (10%) and others (clinical trials, ordering drugs, pharmacoeconomy). According to examined physicians the major benefits of pharmacists employment at the hospice are as follows: decrease in costs of the pharmacotherapy (53%), proper drug storage (50%) and improvement in the access to drugs (47%).

**Conclusion:** Generally, the cooperation between physicians and pharmacists at Polish residential hospices considers administrative and organisational activities rather than the clinical ones. Physicians who actually cooperate with a pharmacist are more enthusiastic about his incorporation into therapeutic team than those who have no experience in working with a pharmacist.

**Abstract number:** P1-216

**Abstract type:** Poster

## Out of Hour Palliative Care Consult Service for Patients in Brasov County Romania

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**Background:** The national palliative care strategy is describing 3 levels for delivering care according to complexity of cases:

- 1-support for self care;
- 2-general palliative care;
- 3-specialised palliative care.

Specialised services apart of delivering direct care to patients with complex needs have the role to offer support for the first 2 levels. Our specialised palliative service is caring for around 1200 new adult patients yearly in home care, outpatients, inpatient, and day center. It has piloted since February 2014 a consult telephone service (CTS) for out of hours available from 4 pm to 7 am and weekends. It is staffed with highly trained palliative care nurses, who can access if needed the on call palliative care doctor.

**Aim:** To analyse the activity of the CTS in the first 7 months of existence.

**Method:** Retrospective study done by reviewing entries in the CTS database and documentation included in files of patients who received a CTS intervention between February 1<sup>st</sup> to August 30, 2014.

**Results:** We identified 1853 interventions grouped in 2 main categories: monitoring calls 62,17% - initiated by hospice staff for follow up of patients in the community and patients/family member calls in 37,83%(694 cases). Reasons for calls in the second category: uncontrolled symptoms 38% (pain 66,53%, neurological problems 49,38%, nausea and vomiting 26,53%, etc); need for information 22,96% (new admission, transition in services), problems with medication 11,15%, nursing needs 9,98% terminal care 9,84%. The average duration of a call was 10 minutes. The nurses needed doctor backup in 3% of cases. Solution to patients and family calls was: solved by phone 74% of cases, family requested to come to the hospice 9%, home visit of the team the following day 12%, advice to call 112- 5%.

**Conclusion:** The CTS proved to be effective and needed. Staffing with nurses of CTS is an adequate choice. Symptom control was main reasons for calls.

**Abstract number:** P1-217

**Abstract type:** Poster

## Ethical Issues within the Nursing Home: A Systems Approach

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**Aim:** The aim of this review is to illustrate the organisational factors associated with ethical issues experienced within the nursing home from the care-providers point of view. This was achieved as part of a larger review which considered four factors associated with ethical issues in the nursing home.

**Method:** Aveyard's (2014) recommendations for systematically conducting a literature review in health and social care were adhered to. Four search strategies were implemented which aided the retrieval of research papers based within nursing homes, involving nursing staff and focusing on ethical aspects of care. A total of 37 papers were retrieved.

**Results:** Four themes emerged; individual, group, organisational and societal factors, which were linked to ethical issues. Focusing on the organisational issues, the overall structure of care was viewed as unsupportive of person centred care. Nursing homes consisted of low doctor: resident ratio, limited guidelines for communication with residents and relatives, a communal set up which overlooked individual needs, and a culture of misusing or overusing restraint. Lack of resources and limits to the care available left care providers experiencing ethical issues regarding the best way to provide the standard of care they felt was essential for older adults. No papers were retrieved which specifically covered ethical issues experienced by nursing staff during palliative care provision within the nursing home, revealing a gap in the literature.

**Conclusion:** Organisational issues are often difficult to resolve, however, further research could explore what ethical issues care-providers deal with most frequently and develop recommendations for a redistribution of resources in nursing home care. Further research may also consider looking specifically at palliative care within the nursing home. This study is funded by the Queen's University Belfast (School of Nursing and Midwifery)

**Abstract number:** P1-218

**Abstract type:** Poster

## Rehabilitation in Palliative Care: Improving Quality of Life?

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**Background:** Advances in treatment techniques have been associated with increases in cancer patient survival rates. For many patients, cancer is now seen as a long term condition involving multiple treatments that may at times be very disabling. Physical disability affects most aspects of life and leads to depression, increased caregiver needs, poor quality of life and health care resource utilisation. Rehabilitation aims to improve the quality of survival, helping people adapt and lead fulfilling lives with minimum dependency regardless of life expectancy. Rehabilitation strategies contribute to palliative care by maintaining and, if possible, promoting functional independence during a period of expected physiological decline. At the Marie Curie Hospice West Midlands a 12 week rehabilitation programme has been developed for post palliative chemotherapy cancer patients.

**Aims:** The programme aims to improve patients' quality of life. It uses a patient centred multidisciplinary approach to maximise physical and psychological function through a tailored prescription. All patients attending are assessed by both a medic and a physiotherapist at weeks 0, 6 and 12.

**Methods:** Patients who commence the programme complete the Palliative care Outcome Scale (POS), The Brief Fatigue Inventory (BFI), and if appropriate a breathlessness scale and/or GAD-7 at weeks 0, 6 and 12. Comparison of questionnaire scores for each patient at weeks 0, 6 and 12 will be recorded and evaluated.

**Results:** Early results show that patients participating in this programme are showing improvements in their POS scores and their BFI scores as they progress through the 12 weeks.

**Conclusion:** At present this programme is only available to patients who have recently completed palliative chemotherapy. However, the next step will be to offer this programme to patients with a palliative cancer diagnosis regardless of the oncological treatment they have received.

**Abstract number:** P1-219

**Abstract type:** Poster

## Coordinate My Care - Intelligent Data Informs Intelligent Clinical Practice and Service Provision

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**Aims:** Coordinate My Care(CMC)is a clinical service underpinned by an electronic solution. The aim is to provide patient information about those at end of life or with specific care needs that have been agreed between clinician and patient. Information is stored on a record which can be accessed and updated 24/7. CMC is a platform to facilitate change in how care is delivered to patients with complex needs. Successful outcomes of CMC rely upon accurate and intelligent data collection and analysis. For optimum clinical practice and service provision, data must be viewed and utilised as both a driver for and result of change.

**Methods:** The team regularly analyses data about all aspects of CMC-numbers of clinicians trained to create records and use the system-7010;numbers of records created across London-17919 and speciality creating records-community 20%, GPs 26%, Hospice 33% Acute 21%. This is correlated with the economic,health and social data associated with each borough. In areas where fewer records are being created, education and training may be proffered as a solution. The data thereafter are closely monitored for exponential growth.

**Results:** Needs peculiar to each demographic locality are being addressed and responded to appropriately. Patient care and clinician performance is fully auditable. Areas of strong practice and areas in need of support in both palliative care and CMC are being highlighted and responded to by CMC. Data are shared throughout different localities to share good practice for learning and development purposes.

**Conclusions:** Data must be analysed regularly to ensure that any service is providing evidenced, clinically sound patient care. Data are an intrinsic part of any service provision, to be used from conception and throughout delivery to measure success. Changes in data must be analysed and responded to appropriately. Data are both a driver for and a result of change. Some aspects of clinical practice can be measured by data analysis.

**Abstract number:** P1-220

**Abstract type:** Poster

## Migrant Dying - Challenges for Service Providers and Needs of the Migrant Population

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**Background:** In the course of emerging Palliative Care (PC) policies in Switzerland, there is a growing interest in the needs of migrants. The authors recently conducted two studies addressing this. First, a needs assessment was done in 2014, mandated by the Swiss Federal Office for Public Health. Second, a research project (2012-14), funded within the National Research Program 67 'End-of-Life' (EoL), is exploring how the old-age nursing home is dealing with migrant dying. Both projects focus on how migrant patients might be challenged by and challenge PC and EoL services.

**Aims:**

- 1) Exploring main challenges to equal access to PC and EoL services, and challenges for services to offer equitable high-quality services.
- 2) Recommendations for policy and practice measures.

**Methods:** The needs assessment included

- a) an international literature research,
- b) a rapid ethnographic appraisal (interviews and focus groups with migrants)
- c) and telephone interviews with 10 specialised PC services.

The study on nursing homes is based on extensive participant observation of interactional co-constructions of 'doing death' and 'doing diversity'. Analysis followed the principles of Grounded Theory.

**Results:** Main challenges for patients and services are

- a) differing views of adequate communication (direct/indirect), of „good death“, and of proxy decision-making,
- b) high confidence of migrant patients in professional services, but focus on curative care,
- c) need of providers for institutionalised transcultural support and need of patients for advocacy,
- d) only weak and informal networks between services and migrant organisations.

**Conclusion:** Measures to improve PC services should mainly focus on: training professionals in communication skills and in reflecting their own values, raising awareness of EoL issues and knowledge on PC services in the migrant population, developing local networks between PC providers and migrant communities (religious specialists, social workers, interpreters).

**Abstract number:** P1-221

**Abstract type:** Poster

## How Is Ascites Managed in UK Hospices?

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**Background:** Ascites is a cause of distressing symptoms for patients and in 2012-13 there were almost 37,000 finished consultant episodes (over 207,000 bed days) for patients admitted for paracentesis in English hospitals. Hospices can manage this problem too, but there is perceived variability in how hospices support these patients.

**Aims:** To survey the current management of ascites in adult hospice inpatient units within the United Kingdom.

**Methods:** An electronic questionnaire created using Survey Monkey® was distributed to 191 UK hospices with inpatient units identified via the 'Help the Hospices' directory and weekly newsletter. Consent was implied by response to the questionnaire.

**Results:** 78 units responded to the survey (a 41% response rate). 57/78 had performed a paracentesis in the last year and 21/78 answered that they had an ultrasound scanner. Of those that had not performed a paracentesis the main reasons were: lack of ultrasound scanner, belief that patients got a good service in hospital, and lack of expertise. Only 7 units never used ultrasound before paracentesis.

Just 3 units always provided an information leaflet prior to paracentesis, and 21 said they would always ask a patient to sign a consent form. 59/78 said that they prescribed diuretics, but only 8 said that they thought the Serum-Ascites Albumin Gradient helped this. Only 18 respondents knew the referral criteria for semi-permanent drain insertion.

**Conclusion/discussion:** Our results show considerable variability in the management of ascites in UK hospices. The majority of responding units did not have their own ultrasound scanner but few would perform paracentesis without prior ultrasound. Provision of information leaflets and the requirements for written consent varied. Diuretic use was common and many did not know the referral criteria for semi-permanent drain placement.

**Abstract number:** P1-222  
**Abstract type:** Poster

## Specialist Palliative Care Involvement in a Cross Sector Multi Professional Approach in the Care of Frailty Patients with Complex Long Term Conditions in a North London Borough

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**Background:** With an increasingly aging population there are more frail patients than ever with multiple physical and mental health co-morbidities. Frailty refers to a patient's vulnerability when dealing with stressors. A north London borough has developed an innovative cross-sector multi-professional approach to manage the most complex of these frail patients focused around a weekly Integrated Care Hub meeting. Specialist palliative care was invited to contribute to this frailty work.

**Aim:** The aim of the project was to provide earlier access to specialist palliative care for patients with long term physical and mental health conditions; to guide patients, families and professionals in the advance care planning process promoting patient choice in place of care and death. To work alongside primary and secondary care, social care and voluntary organisations supporting colleagues in decision making in complex care management.

**Design:** Two whole-time equivalent clinical nurse specialists were funded from the Clinical Commissioning Group Integrated Care budget for 2 years.

**Results:** Halfway through the project 34% of all referrals to palliative care were identified as 'Frailty' patients in the north sector. 19% of these had a cancer diagnosis. 43% of these patients that died on our case-load. Of these 96% died in their or their families preferred place of care. These patients previously had a high chance of dying in hospital. 34% of the frailty patients had a short to medium palliative care intervention and were then discharged. 22% remain on the case-load. The palliative care teams have had an increase in collaborative working practices with other professionals.

**Conclusion:** Specialist palliative care services have an important role to play in the management of frail patients with complex needs. The evidence presented here shows that our involvement does help maximise patient and family choice at the end of life thus reducing hospital deaths.

**Abstract number:** P1-223  
**Abstract type:** Poster

## The Gold Standards Framework Acute Hospital Programme to Support End of Life Care in hospitals

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**Background:** GSF is a well-used UK service improvement/training programme in end of life care for generalist frontline staff UK to improve care for people in the final years of life. Since 2008 the GSF Acute Hospitals Programme has been used by over 40 acute hospitals with several progressing to accreditation. Research confirms that 30% of hospital patients are in their final year of life, yet few previously identified this many patients to begin proactive care.

**Aims:** The programme aims to improve the quality of care, cross-boundary coordination and collaboration and to decrease hospitalisation, enabling more to live and die at home. It includes teaching and assessing against the three GSF steps of identify, assess and plan and provides workshops, resources, coaching and independent evaluation.

**Method:** A comparative evaluation is undertaken in each hospital ward including key outcome ratios, audits of patients (After Death/ Discharge Analysis), staff confidence, organisational change and qualitative data. The programme is independently evaluated and hospitals are benchmarked.

**Results:** The key results included

- § Improvements in staff knowledge and confidence in most areas of end of life care
- § Reduced length of hospital stay
- § Earlier identification of patients in the final year of life - about 30% - and appropriate specialist referrals.
- § More advance care planning discussions
- § Improved communication with primary care
- § More rapid discharge processes and care planning for the last days of life

**Conclusion:** GSFAH enables hospitals to improve their quality of end-of-life care at grass roots level delivered by generalist frontline teams, with better referrals to specialists, offering broadened awareness, more proactive care and improved communication. Use of GSF in acute hospitals is a major factor in developing the model of integrated cross boundary care. Accreditation enables wards to receive the Quality Hallmark Award and to be recognised by the regulator CQC.

**Abstract number:** P1-224  
**Abstract type:** Poster

## Long Term Sustainability of Best Practice in Care Homes - Using the Gold Standards Framework Care Homes (GSFCH) Training and Accreditation Programme

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**Context:** With over 25,000 care homes in UK caring for some of the most vulnerable people, and about 20% people dying in care homes, can we develop a national momentum of best practice that enables effective and sustained top quality care? Many receive suboptimal care with high hospital admission rates at the end of life. About 50% hospital admissions are thought to be preventable with better proactive care.

**Aim:** The GSFCH quality improvement programme aims to effect organisational and culture change leading to sustained improvements in care for all residents, to ensure quality assurance and quality recognition so that 'gold standard becomes standard care' for all.

**Method:** Intrinsic evaluations within the GSFCH programme are described. Accreditation assesses the care home against 20 quality standards ensuring the standards are embedded and sustained, evidenced by portfolio, ADA audit and a robust assessment visit.

**Results:** Evidence from over 2,500 care homes trained, almost 500 accredited and over 100 reaccredited after 3 years reveals sustained improvements in EOLC and ACP, showing a positive impact on the quality of care received toward the end of life. Portfolios of evidence, feedback from relatives and residents, and whole team involvement show that staff identify, code and anticipate the needs of residents, demonstrate continued practice improvements through audit and reflective practice, and are more proactive in their care, thereby reducing crises, hospital admissions and enabling more to die at home.

**Conclusion:** The GSF reaccredited homes have maintained and improved their standards of care and ACP uptake - not just standard practice but enhanced practice - ensuring consistency, continuity and sustainability. We can now be confident that residents in GSF Accredited care homes receive 'gold standard' care that this is sustained. Working with the regulator CQC, GSF is becoming part of the industry standard across the UK as a national model of best practice.

**Abstract number:** P1-225  
**Abstract type:** Poster

## GSF Improving End of Life Care in Primary Care

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**Background:** Most UK GP practices adopted the principles of Foundation Level GSF (bronze) i.e. a GSF/Palliative Care Register and a meeting to discuss them. The 2010 National Primary Care Audit confirmed that only 25% of people who died were included on the register. Most were cancer patients but importantly, those on the register received better coordinated care. Therefore Next Stage GSF was developed with 'Silver' and 'Gold' quality improvement programmes, plus Accreditation and the RCGP endorsed Quality Hallmark Award.

**Aim:** To improve the early identification of patients to ensure equity of access, improve assessment both clinical and personal through Advance Care Planning (ACP) discussions and improve collaboration and coordination of care reducing unnecessary hospital admissions and the associated costs.

**Method:** The GSF 'Going for Gold' quality improvement programme is a 6-module practice-based training programme with a robust evaluation process. Evaluation includes: Key outcome ratios - evidence of measurable change before and after training intervention Audit

- a) Patient level - After Death Analysis sample
  - b) Staff confidence
  - c) Organisational changes
  - d) Qualitative Patient/carer/staff feedback
- Practices can then progress to accreditation with a portfolio of evidence and assessment visit/ phone call.

**Results:** The results following accreditation of the first 10 practices showed significant improvements including more identified early and included on the register, from care homes and with non-cancer having advance care planning and DNACPR discussions carer assessment and support reducing hospitalisation.

**Conclusion:** Significant improvements were seen in all accredited practices. Particular improvements included earlier identification for the register leading to better systematic care of patients. Additional benefits were improved confidence of staff and pride in this area of work and 'cultural change in care, especially for the frail elderly.

**Abstract number:** P1-226  
**Abstract type:** Poster

## Hospices in Denmark - A Common Program for Research, Development and Documentation (RDD)

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**Background:** The first Danish hospice was established in 1992 and now there are about 18 hospices with 9 - 24 beds each and 250 beds all in all. While the first hospices were private institutions, all the hospices are now defined as specialised palliative care institutions and part of the public health care system. This development holds certain challenges. The one to be addressed here is the demand for research, development and documentation (RDD). How do we combine the general and growing demand for documentation and evidence with a research based understanding of what is assumed to be the special role and content of hospices?

**Aim:** To develop and promote a program for research, development and documentation (RDD), that catches the role, the essence and the quality of palliative care in Danish hospices.

**Methods:** The project is organised as a cooperation between the association of leaders at Danish hospices and researchers from PAVI, Knowledge Centre for Rehabilitation and Palliative Care. Since 2012 we have been discussing the challenges of RDD in Danish hospices - and the possibilities for further development. In 2014 the hospices decided to work on a common research program (2015 - 2020) designed as:

A network between leaders and researchers  
A background study (international literature study, national study of RDD in Danish hospices)

A strategy for RDD, including a theoretical and methodological framework  
A plan for studies to be made across hospices

**Results:** At the EAPC conference 2015 we will present the program.

**Conclusion:** To develop evidence based practice in the Danish hospices, leaders, professionals and researchers have to work together on the basis of a common strategy of RDD, and the framework of RDD must be able to contain multiple designs and methods.



**Abstract number:** P1-227

**Abstract type:** Poster

## Out of Hours Nurse-led Telephone Service in a Greek Home Palliative Care Unit. Preliminary Results

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**Background:** Out-of-hours (OOH) telephone support to cancer patients, and their caregivers, is an essential element of quality service.

**Aim:** To assess the needs of cancer patients, receiving home palliative care (HPC), during OOH and subsequent interventions.

**Methods:** Prospective data from an OOH, nurse-led, call service of a HPC program, for cancer patients, was collected from November 2013 to June 2014. Epidemiological data of callers, characteristics of calls, requests, and interventions were recorded. The calls were then split or merged according to callers' request on a 24hour basis, thus comprising the study sample.

**Results:** Fifty six out of 98 (57.1%) patients cared for during the study period used the OOH service (406 calls). There were 322 requests, mostly by patients' children (32.0%). Most callers (89.4%) had one request, of 4.3 min mean duration, usually in the afternoons on weekdays (45.5%). Symptom/Problem (54.7%) were more prevalent, followed by information needs (18.9%) and pharmacological issues (15.2%). Physical symptoms (69.4%), mostly pain (21.3%) and end of life issues (13.6%) were more frequent in the Symptom/Problem category. Information Needs category included practical matters (32.8%), death (21.3%) or exam results' announcement (16.4%). Nurses characterised 52.8% requests as 'emergencies', more often the Symptom/Problem category (68.2%) and among them physical symptoms and end of life issues ( $\chi^2(4)=44.1$ ,  $p<0.001$ ). Advising and supporting callers was the most frequent intervention 41.6%, along with pharmacological modifications in 37.9%, or practical issues (13.0%). Nurses were able to effectively address 69.3% of requests by phone, while a physician's advice was needed in 22.7%. Hospital admission was advised in 2.5%, and there were also 3 home visits.

**Conclusion:** Telephone consultations by palliative care nurses, can address patients' and caregivers' needs during OOH effectively, without a home visit, or inappropriate hospital admission.

**Abstract number:** P1-228

**Abstract type:** Poster

## Dementia Friendly Palliative Care: Are we Confident?

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Palliative care has not traditionally been involved in supporting people with dementia but, as a specialty, is recognising the need to do so, particularly in the context of David Cameron's Dementia Challenge (2012). At least 50% of the UK nursing home population have dementia as a co-morbidity or primary reason for needing care. Given the ageing population, we need to develop a local service to support people with dementia. Therefore our hospice staff need to be competent to provide palliative and end of life care (EOLC) in this context. Anecdotally our hospice staff feel under prepared for this challenge, so we disseminated a survey to guide education initiatives and support service development.

Between February and March 2014 we opened an online survey to all clinical and non-clinical staff including line managers and volunteers, to gather organisation wide data as a baseline. The questions we devised were based on the Department of Health document 'Common Core Principles for Supporting People with Dementia' generating quantitative and qualitative data. We used a web-based survey service, dotmailer.com, for data collection; the results were then exported into Microsoft Excel and Word for analysis. Two authors generated agreed codes for analysis of the qualitative data and cross checked any ambiguous answers. As far as we are aware, there is no published data on the education needs of palliative care staff, in particular supporting end of life care in dementia. The results showed a reasonable basic understanding of how early dementia presents and how it may impact on care needs but identified a lack of confidence and perceived skills in providing EOLC for those with dementia. The results will inform hospice service development and future plans for developing competence frameworks and education. In order for our organisation to become truly dementia friendly, more education is needed, particularly in end of life care, to support people with dementia in our local area.

**Abstract number:** P1-229

**Abstract type:** Poster

## Integration of Haemato-oncology and Palliative Care Services and Staff Perceptions to Referral

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**Background:** Integration of palliative care services (PCS) with haemato-oncology (HO) patients is a quality standard in Britain. Healthcare professionals face difficult management decisions in defining the point at which further chemotherapy is appropriate and when a change to a more palliative approach should be pursued.

**Aims:** To characterise referrals to PCS in patients with HO malignancies and barriers to early and appropriate referral.

**Method:** We reviewed notes for adult inpatients dying of HO disease in a large teaching hospital between 2009-14. Information regarding PCS referral and discussions around dying was collected. A survey was completed by staff regarding PCS input.

**Results:** There were 49 patient deaths available for analysis.

Of 33 patients who received curative therapy, 30% were referred to PCS. Of 11 patients receiving treatment without curative intent, 73% had PCS referral. 4 of 5 patients receiving no therapy were referred. 15 of the 49 deaths occurred in ICU, none of which had PCS input. Documentation of discussions around death took place in 34 cases (69%). Preferred place of death was discussed in 17 of these (35% of total). Review of the multi-disciplinary meeting (MDM) records showed that in only 2 cases a discussion around PCS referral occurred.

**Conclusions:** The majority of patients had a documented discussion about death. Referral rates to PCS were generally high, however none of the 15 ICU patients had PCS input despite

frequent documented recognition of deterioration. This poses the question of whether there is a role for PCS in HO patients in an ICU setting. Documentation of PCS input in MDM meetings was poor, possibly due to subsequent progression of disease, or death being unexpected. Early integration with PCS and HO is a quality standard and the MDM setting provides an opportunity for this. The survey of healthcare professionals confirmed the value of PCS input and that in some cases referral is made too late.

**Abstract number:** P1-230

**Abstract type:** Poster

## Palliative Care in Residential Homes for People with Disabilities

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**Background:** Due to the increasing longevity, people with disabilities are likely to die over a prolonged period of time because incurable, chronic illnesses occur more frequently with old age. Many people die of conditions which are seen as the typical concerns of palliative care services.

**Aim:** The aim of the study was to analyse the situation on aspects of palliative and end-of-life care in residential homes for people with disabilities in Switzerland.

**Methods:** A representative mail survey in residential homes for people with disabilities in Switzerland has been conducted to examine availability of written end-of-life care policies, staff training, as well as the place of dying, the provision of palliative care and the involvement of residents in end-of-life decisions. Topic-guided problem-centred group interviews with carers, nurses and staff of palliative care services have been conducted to get a deeper insight in good practice in order to explore support factors that enhance self-determination and participation of people with ID in end-of-life decisions.

**Results:** As the average age at death in the study population was 25 years lower than the general population, most residential homes are challenged. Furthermore people with disabilities experience a high percentage of end-of-life decisions, but written policies on end-of-life care are only available in one of four residential homes and little training on end-of-life care is conducted.

**Conclusion:** It is important to systematically provide training on end-of-life care within the residential homes for adults with disabilities in Switzerland. Instruments to assess pain and physical symptom as well as the decisional capacity are needed. Advanced planning, for example by means of issuing a greater number of do-not-resuscitate orders, is therefore needed in order to improve the degree of involvement in the end-of-life decisions of people with ID. Furthermore international comparable data should be generated.

**Abstract number:** P1-231

**Abstract type:** Poster

## How Does Palliative Care in the European Region Develop? Identification of Indicators Monitoring the Development of Palliative Care: A Systematic Literature Search

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**Background:** So far the World Health Organization (WHO) Public Health Model presents dimensions of palliative care (PC) development. However, the rapid progress of PC services in Europe suggests generating additional domains for comparison, monitoring and identification of improvement areas.

**Aims:** To identify and organise indicators to monitor the development of PC in the WHO Public Health Model and beyond.

**Methods:** A systematic search was conducted in Embase, Medline, Cochrane Database, and CINAHL during June/July 2014. Keywords and MeSH terms describing PC, indicators and development were combined.

The selection criteria were: language (English, Spanish and German), year of publication (past 10 years), human nature, available abstract and full text. Screening was performed through two reviewers and discrepancies resolved by consensus.

**Results:** In total 3590 studies were identified, of which 130 were included in analysis. Publications originated from America (40%), Europe (22%) and Asia (15%). The years 2005 and 2013 presented the greatest extend of papers covering indicators.

Journals of health/palliative care/cancer, management and nursing focus were outstanding. After extracting all possible indicators the following topics were covered: finances (n= 23), opioid availability (n= 8), education (n= 15), quality management (n= 5), policy (n= 8), resources/ services (n= 63), staff (n= 7), vitality (n= 19), research (n= 6).

**Conclusion:** A variety of papers with possible indicators were identified. Although some of the identified and already established indicators, e.g. mortality rate (per 100.000), are utilised frequently, future research concerning the new ones in relation to validity and feasibility needs to be performed, to be eligible for reorganising the WHO Public Health Model.

**Abstract number:** P1-232

**Abstract type:** Poster

## Benchmarking the Provision of Palliative Rehabilitation within the UK Hospice Setting

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**Background:** Rehabilitation is an important part of a holistic palliative care approach. Evidence for palliative rehabilitation is limited leading to large variation in practice and uncertainty about how best to deliver care.

**Aim:** To benchmark the provision of palliative rehabilitation, exploring the level and range of allied health professional (AHP) staffing, interventions, settings and service evaluation.

**Methods:** National survey of rehabilitation practice within the adult voluntary hospice sector



using a 68 item online questionnaire. Most questions were closed with multiple, non-ranked options. Ordinal data were summarised by median (inter-quartile range, IQR). Frequency counts and percentages with 95% confidence intervals (95% CI) were calculated for overall responses to items.

**Results:** Forty-one hospices across the United Kingdom participated, serving populations ranging from < 50,000 to >1 million with overall staffing from < 20 to >60 full time equivalent employees. All but one hospice considered that they carried out rehabilitation. Hospices employed a median of 1–2 AHPs, most often a physiotherapist, who led rehabilitation services in 78% (95% CI 63, 88) of hospices. The level of AHP staffing did not relate to overall staffing ( $p=0.10$ ) or the population served ( $p=0.22$ ). A wide range of interventions were offered, most frequently on a one-to-one basis and less frequently within a group, including interventions suited to a group format, e.g. exercise. Goal setting was used by 93% (95% CI 81, 98) of respondents, but the process and outcome were rarely documented. Only 37% (95% CI 24, 52) of respondents regularly used outcome measures.

**Conclusions:** These data provide a benchmark to assess provision of palliative rehabilitation in the hospice setting. The large variation in practice, together with the lack of evaluation through goal setting or outcome measurement, highlights the need for evidence-based development in this aspect of care.

Abstract number: P1-233

Abstract type: Poster

### A Good Enough Death?

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**Aim:** Surveys consistently show that up to three-quarters of Australians would prefer to die at home. The local reality is very different - only 16% of people living in Australia and suffering from a terminal illness die at home. The aim of the project is to provide those in NSW who wish to die at home the opportunity to do so and to understand whether this opportunity contributes to a *good enough* death.

**Design:** The Palliative Care Home Support Program is addressing this end of life care gap with three strategies:

1. The provision of **end-of-life packages** for up to 48 hours of specialised supportive palliative home-based care, day or night, provided by community workers specifically trained for the task, and working as part of existing specialist palliative care multidisciplinary teams.
2. The provision of state-wide access to **two collaborative education programs**: one to train and up-skill the supportive palliative community care workers; and one delivered interactively from HammondCare's University-linked Clinical Training Centres in collaboration with community professionals working in end of life care, including GPs, nurses, allied health and welfare staff, supporting care provision in people's homes.
3. Evaluation: Evaluation of quality and outcomes of service provision, impact on bereavement and hope, and independent evaluation of educational programs.

**Results:** One year into a three year program, 84% of people taking up palliative care home support packages have died at home.

**Conclusion:** We have designed and implemented a program covering three quarters of NSW which has significantly improved the opportunity for people in the terminal or deteriorating phase of their illness to die at home.

Abstract number: P1-233a

Abstract type: Poster

### The Changing Landscape of an Outpatient Palliative Care Clinic: Implications for Staffing Models, Resource Utilization, Physical Plant, Proactive Evaluation and Adaptability

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**Background:** Outpatient palliative care for patients with serious illness have been shown to improve quality of life and reduce burdensome symptoms, which may improve patient survival. While oncologic patients account for the majority of patients seen, an increasing number of non-cancer diagnoses are being seen and more is being learned about optimal program structure and growth patterns with changing patient populations. Herein, we report on the development of one such clinic and its growth and evolution over the past six years.

**Growth:** The outpatient palliative care clinic (named SYMPAQ: Symptom Management, Pain and Quality of Life) at Mayo Clinic in Rochester, MN was established in 2008 and had 89 patient visits in its first year. By 2009, the number of patient visits more than doubled to 219. Patient visits doubled again by 2011 to 512 and increased to 681 visits by 2013 reflecting an average yearly increase in patient visits of 60% per year since its inception. This growth has spurred significant staffing and outcome tracking changes.

**Patterns of expansion:** Cancer, predominantly solid tumor malignancies, was the most common diagnosis in patients referred to SYMPAQ clinic in the first two years. However, substantial increases in patients with cardiovascular disease and end-stage renal disease as the primary life-threatening diagnosis have been observed in subsequent years. Similarly, referring clinicians reflect a wide range of disciplines with increasing referrals from primary care providers (up 40%) and pulmonologists (> 3-fold increase) in the last two years.

Additionally, SYMPAQ clinic has improved care continuity, as increases in new consults placed by inpatient teams for patients at hospital discharge have been observed.

**Implications:** Changing clinician referral patterns and a diversification of primary palliative diagnoses will require staffing changes as well as tracking of patient outcome metrics and referring provider satisfaction.

## Education

Abstract number: P1-234

Abstract type: Poster

### The Impact of Palliative Care Nursing Courses on Clinical Practice

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**Background:** Between January 2013 and October 2014, 1360 Romanian nurses have participated in Palliative Care (PC) courses, out of which 306 nurses at both basic and advanced level of education.

**Aim:** To identify the changes implemented by nurses in their clinical practice, after participating at PC introductory and advanced courses.

**Methods:** Phenomenological study, data collected throughout six focus groups, at 3 to 6 months after the courses, in 6 different locations in Romania. Coding and thematic analysis was performed by 2 researchers in parallel.

**Results:** Five domains were identified: new perspective of care, communication, the team in the health care system, the patient and family, decision making. **IMPROVEMENTS** were identified in the care and communication domain:

1. **Care** incorporation of psycho-emotional aspect into physical care; allocation of time for family support; overcome of fear to administer opioids; comfortable in discussing arguments pro and against intravenous infusions at the end of life.
2. **Communication** improved communication makes nurses feel they provide better quality of care, increases self esteem. **BARRIERS** to apply new knowledge into practice were: collusion of family with health care staff and withholding truth from patients; tensions between the theoretical concept of team work and reality; nurses don't assume competences; Romanian health care system deficiencies make difficult the work in teams. Therapeutically decision making belongs to the physician leading to contradiction among professionals.

**Conclusion:** This study shows that PC, introductory and advanced courses, lead to changes in the nurses clinical practice. It is highlighted the raise in awareness regarding other barriers in the Romanian public health care system that need to be overcome.

Abstract number: P1-235

Abstract type: Poster

### Palliative Care Education Needs Assessment of Senior Doctors in a National Referral Hospital

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**Background and aim:** The landmark 2014 World Health Assembly resolution emphasises the need for integrated palliative care (PC) education and evidenced based service provision. In Uganda PC has been integrated into the undergraduate curriculum since 2004 with an innovative postgraduate internal medicine curriculum since 2009. On seeing the impact of effective PC, senior clinicians requested that their training needs also be met. This reflects the values based change within the senior staff and is essential to ownership and leadership.

**Design:** Using an online survey tool we designed and circulated a questionnaire to identify confidence levels, training gaps and education preferences relating to PC of the senior doctors. Derived themes formed the basis for a qualitative study using focus groups to explore the underlying beliefs and values and facilitate effective training.

**Results:** Survey results reveal highest levels of confidence in the PC concept, basic communication and use of morphine. Lowest levels were revealed in research, self care, spiritual care and bereavement. However the focus of the training requests remained symptom control and pain management with a preference for e-learning. We will use the focus groups to further explore these emerging themes. In particular the unsurprising lack of confidence in spiritual and self care reflects poorly on conventional training and yet are key to effective PC and a resilient senior workforce.

**Conclusion:** Models of health system integration and training for palliative care must address the needs of senior clinicians who will be key role models for any system change. As palliative care gains credibility, training programmes need to be flexible, robust and address areas other than physical care. Palliative care offers an opportunity to challenge and develop holistic values based integrated care for all staff.

**Abstract number:** P1-236

**Abstract type:** Poster

## Supporting Family Carers in Home-based End of Life Care: Using Participatory Action Research to Develop a Training Programme for Carer Support Workers

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**Background:** Family carers provide much of the care for relatives who are dying. They often face great difficulty in doing this, not least as this is a new experience for them.

**Aim:** To develop and pilot a training programme (TP) for volunteers and paid workers who support carers in providing end of life care at home.

**Methods:** An action research approach was used. Workshops were attended by key stakeholders from carer support agencies, palliative care and bereaved carers. These explored the learning needs of and challenges faced by carer support workers in both paid and volunteer roles. A programme was developed to address identified learning needs, using the domains of an evidence based carer support needs assessment tool (CSNAT) as a framework. The TP was drafted and then piloted with developers acting as facilitators. A second pilot took place with independent facilitators. Individuals (n=24) from different organisations took part in the pilots. Evaluation of the TP included by an independent evaluator, completion of participant feedback forms on the day (n=22) and interviews (n=8). The TP was modified iteratively, based upon feedback.

**Results:** An innovative, introductory TP for those who support lay carers providing home-based end of life care. Learning materials include activities and discussion topics, case studies, film of bereaved carers talking of their experiences, and taught elements. The programme has been well evaluated; comments include 'well explained', 'interesting', 'informative discussions', 'very practical'. The programme will be free at point of use and published online. It is designed as a one day programme, with ideas for further activities to allow facilitators to tailor to their local needs.

**Conclusion:** Participatory methods enabled the development of a training programme that is acceptable to a number of key stakeholders and evaluated well by carer support workers. Further research is needed to assess the impact of the programme on practice.

**Abstract number:** P1-237

**Abstract type:** Poster

## Optimising Care of the Dying in the Australian Acute Care Setting

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**Background:** More than 50% of Australians die in acute hospitals. Despite this, there is no accepted minimum standard of care and significant variations exist. Reports continue to identify that the care provided to such people at this stage of life may be less than ideal and that care of people dying in hospitals need to improve. A care bundle was developed to improve the quality of care delivered to dying people in acute hospitals and a pilot of this was undertaken in a regional teaching hospital in New South Wales. Implementing such a bundle requires the provision of structured education to medical and nursing staff.

**Aim and design:** In order to facilitate the delivery of necessary education to support the bundle, a spaced education was developed. This was based on information extracted from best available evidence to inform care of the dying. Two distinct components to the package were developed: 1) General education regarding palliation; 2) discipline specific components for medical and nursing staff.

**Points for discussion:** Online education is popular in Australia given the difficulties in providing face-to-face education to remote locations. Given the need to upskill all health staff in palliation, this type of education may improve end of life care provision in acute hospitals. Online learning addresses the challenges of educating large numbers of staff at separate locations in a static funding environment. Spaced education has been proven by RCT to be effective in clinical settings and to prolong information retention. The challenges of providing education for staff at various levels and of filling a basic knowledge void with regards palliative care itself are significant.

**Abstract number:** P1-238

**Abstract type:** Poster

## Developing a Palliative Care Competence Framework - Lessons from Ireland

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**Background:** The National Clinical Programme for Palliative Care identified the development of a Palliative Care Competence Framework as a key objective and convened a Project Steering Group to support, guide and oversee this development.

**Aims and objectives:** The aim of the project was to develop a Palliative Care Competence Framework for health and social care professionals working across a range of care settings.

**Description of innovation:** The Project Steering Group undertook an initial analysis and evaluation of existing competence frameworks, from the UK, US, Canada, Australia, and Northern Ireland, in order to agree an approach to the framework development in light of this analysis.

Six Domains of Competence and indicators (core competences) describe what health and social care professionals should know at point of professional registration. These core competences formed the basis for the development of Discipline Specific indicators for ten health and social care professions providing generalist and specialist palliative care.

**Conclusions and implications:** The Palliative Care Competence Framework provides for core competences for all health and social care professionals whilst also detailing discipline specific competences up to specialist level. The framework will inform academic curricula

and professional development programs for health and social care professionals. The framework will also enhance the care of people with life limiting illness, and foster greater inter-professional and inter-organisational collaboration in palliative care provision. The outcome of the project is a clear framework to support evidence-based, safe and effective palliative care for generalist and specialist practitioners irrespective of place of practice.

**Abstract number:** P1-239

**Abstract type:** Poster

## Dignity Care Intervention Ireland (DCI Ireland): Pre and Post Education Evaluation for Nurses Working in the Community Setting

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**Background:** Maintaining the dignity of the individual being cared for is key to the provision of palliative care. Nurses working in the community setting require knowledge and skills to meet the needs of service users and their families in need of a palliative care. DCI Ireland is a community based pilot project implementing a dignity care intervention for individuals, with life-limiting illness.

**Aim:** To evaluate the impact of a targeted education programme regarding Palliative Care and the DCI Ireland for nurses working in the community setting in Ireland.

**Methods:** An educational programme was developed for nurses working in the community in four pilot sites (n=54). The education programme consisted on two elements:

1. An on-line programme incorporating an Introduction to the Principles of Palliative Care and their application in clinical practice and the DCI Ireland.

2. Two facilitated workshops for further elaboration of the DCI Ireland.

Case studies were used to support role play by participants in order to demonstrate how and when to use the intervention. Each participant was invited to complete a Pre and Post Education Questionnaire.

**Results:** Findings indicated that in general, community nurses were aware of the principles of palliative care but had some difficulty articulating their use in practice. Overall nurses who completed the education programme felt their knowledge and understanding of the principles of palliative care and their application in practice as well as the importance of dignity preserving care was improved.

**Conclusion:** The importance of education about palliative care and the provision of dignity preserving care cannot be underestimated. Ensuring nurses have the requisite knowledge will contribute to the future development of practice and subsequent improved care for patients approaching the end of life.

**Abstract number:** P1-240

**Abstract type:** Poster

## Junior Doctors Caring for the Dying: What Do They See, Do and Need to Perform this Role?

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**Background:** In their first year of work, newly qualified doctors care for patients who are dying, but many feel unprepared for this role. The Liverpool Care Pathway (LCP) for the dying was designed to facilitate guidance of this care, but a recent national review has led to it being phased out from acute hospital trusts in the UK.

**Aims:** To explore the experiences of junior doctors caring for the dying to develop an understanding of their perceived abilities and attitudes around this role; what they do, what they observe others doing and what they perceive they need to perform this role following the LCP being removed.

**Methods:** Electronic questionnaire to all new junior doctors working within one Deanery in the UK.

**Results:** Ninety-four junior doctors responded (45% response rate). Junior doctors perceive that for the majority of patients, consultants were involved in the decision making process of recognising when someone is dying. Many, but not all (60%) observe their consultants caring for the dying. Junior doctors perceive anticipatory medications are prescribed for patients and appropriate discussions are had with patients and family members about nutrition, hydration and why the patient is now thought to be dying. Despite this, junior doctors perceive only 50% of patients are 'optimally' cared for on acute hospital wards. Junior doctors perceive they need support and training in this area of care, especially with the assessment of symptoms and their subsequent management.

**Conclusion:** Most junior doctors observe consultants recognising when someone is dying, yet many do not observe consultants delivering subsequent care. Junior doctors feel most healthcare professionals are engaging patients and families in appropriate conversations about death and dying, yet bereaved families in other studies suggest such conversations are not clear, and are euphemistic. Junior doctors perceive they need formal guidance to help them care for the dying since the removal of the LCP.

**Abstract number:** P1-241  
**Abstract type:** Poster

## Demonstrating Medical Student Competency in Palliative Care: Development and Evaluation of a New 'OSCE' Station

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**Background:** Primary palliative care skills are important for most physicians but an authentic assessment tool using standardised patients has not been reported for medical students. **Aims:** To develop, implement, and assess the characteristics of a palliative care observed structured clinical examination (OSCE) for 4<sup>th</sup> year medical students. In its second year, we modified the case to prepare it for future use as an evaluation tool. **Methods:** Incorporating palliative care and education expert input, we created a representative case and a checklist of 16 history questions in five domains. In its second year, based on review of the first year analysis and further expert input, we revised the checklist to 14 history items in three palliative care domains. We also trained a new standardised patient with an acting background because the first SP found the daily emotional toll too hard. Each of one hundred rising 4<sup>th</sup> year medical students completed this case and 7 others in a single day as part of a required evaluation. We performed standard item analyses on the history items and determined inter-rater reliability. **Results:** The one hundred students scored an average of 75% (sd 13) on the 14 history items up from 64% (sd 12) on 16 items the previous year. There was 95% (from 94%) agreement in ratings on the history items between the SP and a remote observer. Of note, the students performed better on the MIRS communication skills questions on the palliative care case than on any other case. The students reported that the case seemed authentic. **Conclusions:** A palliative care OSCE is feasible to implement with high inter-rater reliability. We found that using a professional actor as the standardised patient is an improvement for this emotionally demanding case. Analysis of the OSCE's performance demonstrates successful aspects in assessing student competencies in primary palliative care.

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**Abstract type:** Poster

## (Lack of) Training for Uncertainty: A Review of Training Curricula and Published Literature

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**Background:** Uncertainty is common in illness, particularly advanced illness with uncertain prognosis, and we know that patient quality of life is affected if uncertainty is poorly addressed. Addressing uncertainty is therefore a key skill for health care professionals (HCPs). **Aim:** To determine what HCPs are expected to learn about addressing uncertainty; and to synthesise professionals' views of their ability to manage uncertainty. **Methods:** We reviewed UK undergraduate and postgraduate medical and nursing curricula (identified from training body websites) for content related to addressing uncertainty. We also undertook a limited systematic literature review and narrative synthesis. We searched Medline, Embase and PsycINFO for 'uncertainty', 'Professional Competence', and related terms. Inclusion criteria were data on views of HCPs relevant to competencies in addressing uncertainty, or analysis of HCP practices. **Results:** We identified 19 curricula and 3220 articles. 142 full text articles were screened and 40 were included. Aside from primary care, paediatrics, public health and ophthalmology; curricula contained only generic references to uncertainty e.g. 'communicate effectively in uncertain situations'. 6/19 curricula contained no mention of uncertainty. In included articles, barriers to addressing uncertainty were reluctance of HCPs to have conversations relating to uncertainty, difficulty acknowledging the legitimacy of uncertainty, and concerns about causing iatrogenic harm by 'unnecessary' information provision. Initiation of discussion by patients or families, and spacing discussions over several sessions were facilitators. HCPs frequently reported inadequate competence in addressing uncertainty. **Conclusion:** HCP competencies related to uncertainty are not explicit in curricula despite the training needs reported by professionals. Addressing and communicating uncertainty are therefore areas in which HCPs need more training than currently exists.

**Abstract number:** P1-243  
**Abstract type:** Poster

## The Leadership Development Initiative: Improving Physician Leadership Skills

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**Aims:** The Leadership Development Initiative (LDI) was created with the goal of increasing leadership skills among international palliative care physicians and enhancing palliative care globally. This study summarises findings from the Cohort 2 *Core Skills Survey* and the *Post-LDI program evaluation*, with the aim of understanding the physician's self-perceived leadership skills and the resources that the physicians valued throughout their LDI leadership journeys. **Study design and methods:** Physicians were asked to complete a *Core Skills Survey* and rank their self-perceived leadership skills before beginning LDI and again after each LDI course. When completing the survey after the second residential course, physicians were asked to 'retrospectively' rate their core skills, looking back to before they started the program. Physicians also completed a Post-LDI evaluation which included 16 questions in which they rated the value of skills presented across the LDI courses and provided comments noting the impact of their experiences in the LDI program. **Results:** Results showed that leadership core skills increased significantly with each training (p < .01). In addition, physicians reported (in rank order) that their greatest resources for success were  
1) LDI experience and courses (29%),  
2) having a stipend (29%),  
3) mentorship advice (27%), and  
4) networking (21%).

In addition, 100% of leaders responded noted that participating in LDI helped them: 'Teach more or better', 'Lead self' more or better, 'Lead others more or better', 'Learn more or better', and 'Advance PC in their context'. **Conclusion:** International physicians reported increases in self-perceived core skills and described several resources which attributed to their success. Overall, they felt that participating in LDI contributed to their success as leaders and in advancing palliative care in their countries.

**Abstract number:** P1-244  
**Abstract type:** Poster

## Stepping Forward: Sustaining Quality End of Life Care in Care Comes Following on the Six Steps to Success Programme

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**Background:** In an area (pop 235,000) with 112 care homes (3400 beds), the Six Steps to Success Programme supports delivery of high quality End of Life (EoL) Care. 45 homes achieved accreditation and a further 12 in next cohort. As a result, care homes have systems in place to identify residents approaching EoL, provide care and support families. Completing the programme and sustaining the changes made, is demanding yet rewarding. **Aim:** To support care homes to continue delivering high quality EoL following completion of 6 programme, reduce unnecessary hospital admissions and enable residents to be cared for and die in preferred place of care. **Method:** Support initiatives include: delivery of cross boundary EoL education and support from local Specialist Palliative Care Service (SPCS) and TRANSFORM Team; monthly visits and regular telephone calls; collection and collation of data from homes; those approaching end of life are included on cross-boundary register; flags on admission to hospital enable TRANSFORM to support admission and facilitate smooth transfer between care settings; quarterly link meetings (hosted by hospice) to share experiences and receive updates; syringe driver loan scheme in place for homes who attend competency based training. **Results:** Locally agreed criteria for continued accreditation have been agreed, with the majority meeting the requirements (33/35). The TRANSFORM Team has built excellent relationships enabling timely support, prompting best practice, and identifying and meeting the educational needs of staff. Quantitative data collected helps demonstrate the good work they have done, identify challenges and share good practice, whilst qualitative feedback demonstrates the value, to them, of the support they receive. **Conclusion:** Through collaborative working with SPCS, acute trust and primary care, Care Home staff feel valued in EoL Care. Ideas and enthusiasm are generated by ongoing support for homes dealing with the challenges such as high staff turn over.

**Abstract number:** P1-245  
**Abstract type:** Poster

## Any Time, Any Place, Anywhere: A 7 Day a Week Responsive Palliative Care TRANSFORM Education and Support Team

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**Background:** A well circumscribed area in the North of England already had an integrated specialist palliative care service consisting of NHS community and hospital team and voluntary hospice providing inpatient, day, outpatient and at home services; was in the second national wave of the Transforming Acute Hospitals programme and has started to implement the Six Steps Programme in care homes. **Aims:** To provide a team that works 7 days a week across hospital, community and care home settings to educate and support staff in caring for those patients recognised to be in the last year of life, especially those without specialist palliative care needs, and to proactively seek out and support their families. **Method:** The TRANSFORM team was created, merging TRANSFORM Hospital Clinical Lead and End of Life Facilitator, Six Steps Care Home Facilitators and new posts to embed AMBER care bundle and Advance Care Planning. Consistent education is delivered by the team across all areas with practical support scaffolding learning. Patients likely to be in the last year of life are identified on admission to hospital and support given to ensure a co-ordinated approach to care and smooth transition between settings, whilst respecting wishes and preferences. Strong clinical relationships developed between all services with regular contact with hospital and community teams and care homes. The team supports cross boundary data collection highlighting areas of strength and opportunities for improvement. **Results:** Although only in existence since May 2014, figures already show an increase in numbers of staff receiving palliative and end of life care education and a 30% increase in numbers of dying patients whose wishes to be at home are respected and met. **Conclusion:** A corporate team approach has enabled the development of a trusted and reliable service. The TRANSFORM team empowers and supports all health care professionals to confidently deliver high quality end of life care.



**Abstract number:** P1-246  
**Abstract type:** Poster

## **Palliative Care Education - A Systematic Review of International Concepts within Undergraduate Curricula**

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Differences and deficits have been globally described within palliative care education. The aim of this paper is to compare existing palliative care curricula and to analyse actual concepts in palliative medicine education. A systematic review was conducted in June 2013 which included both quantitative and qualitative publications on the subject. The electronic databases Medline and Google Scholar, searches in relevant journals were used for literature search which have been published within the last decade. Search strategy was: term related with Medical Students AND PC AND Education AND Attitude OR Knowledge OR Skills. Established methods for data collection and extraction were considered to review disparate study designs. 17 publications met inclusion criteria. Most publications were published in the United States (n=9), followed by Western Europe (n=3), the United Kingdom (n=2), the Asia-Pacific area (n=2) and Latin America (n=1). Main differences could be detected concerning methods for assessment and range of undergraduate curricula, whereas duration and timing of palliative care education proved higher consensus. All publications valued highly the implementation of multimodal teaching concepts in their curricula. There was used a wide scope of different assessment methods for measuring palliative care teaching effects on students, making it difficult for comparison. Recent concepts in palliative medicine teachings show promising approaches for pushing forward palliative education and effectively preparing tomorrow's doctors to provide patient centered care and family support. This systematic review highlights the lack of standardisation in palliative care education and assessment methods. Improvements both institutional and legal are needed to take advantage in the opening field of palliative care in undergraduate medical education worldwide.

**Abstract number:** P1-247  
**Abstract type:** Poster

## **An Innovative and Integrated Cross Agency Palliative Care Education Programme for the Health and Social Care Workforce**

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Key areas for workforce development in palliative and end of life care have been identified in the UK National End of Life Care Programme. Multiprofessional education for health and social care workers is recommended to improve quality of care across diverse settings. However, challenges exist with wide variances in knowledge and practice. Educational aims were to facilitate joint learning of core principles of palliative and end of life care, enhance awareness of roles and responsibilities, identify commonalities, critique current practices and identify areas for change. A 3 day programme of reflective practice was undertaken using a social constructivist approach to learning. Managers and junior staff members were separated for part of the programme to enhance articulation of concerns, learning needs and perceived status of current practice. Feedback to whole group was anonymised. 89 participants from 40 diverse health and social care organisations attended. 92%(n=85) evaluations captured improvements in knowledge in key areas to also include the perceived power of reflective practice, recognition of the importance of professional liaison and ethics, promotion of dignity and choice, looking after self and valuing other staff members. 96%(n=88) of participants strongly agreed that reflective activities had facilitated examination of current practices. 172 individual and organisational proposals of practice change were recorded. Themes related to individual and multiprofessional communication, collaboration, education training and reflection, attitude change, teamwork and forward planning. Structured reflective inter/multiprofessional education has the potential to assist in identifying areas for practice development and organisational change to improve care. Further study to examine how many of the 172 changes have been achieved is required to provide evidence of the effect and identify potential barriers to implementation.

**Abstract number:** P1-248  
**Abstract type:** Poster

## **Improving On-line Learning in Palliative Care: A Comprehensive Review**

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**Aims:** To identify the key components of un-moderated elearning models.  
**Background:** A pan-European study examining integrated palliative care in advanced cancer and chronic disease aims to develop an un-moderated (i.e. stand alone, asynchronous and with no student to tutor interaction or feedback) elearning resource to disseminate best practice recommendations. This platform will provide wide access to a free educational programme designed to enhance professional education and practice in palliative and end of life care across Europe and beyond.  
**Methods:** A search of MEDLINE, ERIC, CINAHL, AMED PsycInfo and Academic Search Complete databases was conducted. This yielded 1441 results reduced to 1084 on removing duplicates. Following examination of titles and abstracts 26 papers were selected for narrative review. A bibliometric analysis was carried out to determine trends in published output.  
**Results:** Evidence for the efficacy of un-moderated elearning platforms was lacking in the literature and where evident, was often compromised by other factors more associated with blended learning approaches. These included tutor input, peer interaction through discussion boards or elements of face to face tuition. Un-moderated programmes did not provide evidence of efficacy or impact. However, such programmes were reported to offer improved access for remote learners and those with resource constraints. Additionally,

asynchronous delivery provided flexibility for those studying alongside work or other commitments. Bibliometric analysis demonstrated a steady increase in the number of publications from elearning studies in recent years.  
**Conclusion:** There was little evidence in the literature on the efficacy of purely un-moderated elearning programmes with much of the debate focused on blended learning techniques. The development of un-moderated programmes needs to explore ways in which their impact may be better evaluated and researched.  
FP7-HEALTH funding

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**Abstract type:** Poster

## **Providing Quality End-of-Life Care in an Acute Hospital: Are our Nurses Prepared?**

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**Background:** Nurses play an important role in providing quality end-of-life (EOL) care because the nature of their work involves them spending long hours and working in close proximity with patients and families. Yet, many nurses have expressed inadequacies in EOL care and little research has addressed this issue in Singapore.  
**Aims:** To describe nurses' attitudes towards death and dying using the 12-item self-administered *Attitudes towards Death Survey*.  
**Methods:** This was a cross-sectional study of all nurses from a 590-bed restructured hospital in Singapore. Consent to participate was indicated by completion and return of the questionnaire. Descriptive statistics was used.  
**Results:** A total of 966 questionnaires were sent out. Response rate was 76.2%. Two-thirds of the responders were aged 20-29 years, and more than half (54.5%) had < 4 years work experience. Most of the nurses surveyed were working in the inpatient setting (89.8%), followed by the outpatient setting (7.6%), and in the community (2.6%). More than half of the nurses (52.3%) stated self-perceived inadequacies in EOL care. More than half the nurses (50.3%) felt that 'the end of life is a time of great suffering'. More than a third of the nurses interviewed agreed that little can be done to help someone achieve a sense of peace at the end of life (42.9%), that they were uncomfortable talking to families about death (40.9%), that feeding tubes should be used to prevent starvation at the life (39.4%) and that the use of strong pain medications can cause the patients to stop breathing (37.0%).  
**Conclusion:** This study highlights knowledge gaps, misconceptions, and self-perceived inadequacies about death and dying amongst nurses. Educators and administrators need to recognise the importance of strengthening EOL care education in nursing schools and as part of ongoing educational programs if quality EOL care is to be provided to our patients.

**Abstract number:** P1-250  
**Abstract type:** Poster

## **Six Steps to Success Programme: Improving End of Life Care for Care Home Residents**

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**Background:** Over 425,000 elderly and disabled people live in residential care homes in the UK. Despite regarding the care home as their 'home' a majority of residents are admitted to hospital at the end of their lives. Inappropriate admissions to hospital from care homes at the end of life (EoL), identified within the End of Life Care (EoLC) Strategy resulted in the call for improved education surrounding EoLC for care home staff. Responding to this, three cancer/end of life networks in Northwest England, with endorsement from the National EoLC Programme, developed the Six Steps to Success programme for care home staff. It aims to ensure all residents receive high quality EoLC enshrined in the philosophy of palliative care. Care home staff are supported by an EoLC Facilitator from the local area.  
**Method:** Mixed-method evaluation in 3 phases;  
1) examination of audit data (quality markers and measures; post death information; knowledge skills and confidence audit),  
2) questionnaires and interviews with Six Steps Facilitators and  
3) case studies with 6 care homes.  
Analysis involved descriptive statistical comparisons and frequencies, qualitative data were subject to content analysis to identify themes.  
**Results:** All care homes demonstrated improvements in the use of Advance Care Planning (ACP); the number of residents who died with an ACP in place increased from 45% to 56%. Knowledge skills and confidence around EoLC improved markedly amongst care home staff; there was 92% improvement for Spirituality skills and 79% improvement for ACP knowledge. The number of residents dying in their preferred place of death increased from 81.5% to 83.1%.  
**Conclusion:** The evaluation has shown that this flexible and adaptable model of training for care home staff has undoubtedly improved EoLC in care homes. The Six Steps to Success programme has empowered care home staff to deliver better care for their residents ensuring their wishes and preferences at end-of-life are met.



Abstract number: P1-251

Abstract type: Poster

## The King's College London MSc in Palliative Care at 16 Years: Quantifying the Contribution of Former Students in Advancing the Palliative Care Evidence Base

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**Background:** The EAPC states inter-professional education is critical to promote the specialty of palliative care. In 1998, King's College London developed an inter-professional MSc in Palliative Care that aims to provide students with skills to appraise research and conduct methodologically robust studies, and to advance knowledge and understand the principles and practice of palliative care.

**Aim:** To quantify the contribution of former students in advancing the palliative care evidence base.

**Methods:** Database of MSc students from 1998-2013 was analysed to describe former students' characteristics. PubMed, Google Scholar and Scopus databases were used to identify publications and academic texts first, or co-authored, subsequent to students' graduation.

**Results:** 263 students graduated from the course since its inception. Of these, 85% (n=223) were female. The geographical origin of students varied: 68.8% (n=181) were from the UK, 20.5% (181) were from other European countries and 10.5% (n=28) were from elsewhere in the world. More than half (52.5%, n=138) of the students were doctors, 42.2% (n=111) were nurses and 4.9% (13) were allied health and social care professionals. 109 (41.6%) former students were identified as having published research in scientific journals and/or contributed to academic textbooks. The total number of outputs published was 741 (median 6.81, range 1-91) and included those in the British Medical Journal, Lancet Infectious Diseases, Journal of Pain and Symptom Control, Palliative Medicine and Social Science and Medicine among others. The most heavily cited paper on factors influencing death at home was cited 332 times. Contributions to textbooks included those in the Oxford Textbook of Palliative Medicine and the Textbook of Palliative Medicine.

**Conclusion:** Students who participated in the MSc in Palliative Care have made a global impact on the volume of high quality research used to inform clinical care and palliative care policy.

Abstract number: P1-252

Abstract type: Poster

## Review of the First Romanian Palliative Care Online Course

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**Background:** The online palliative care program(OPCP) was developed in partnership between the local hospice and the Medical Faculty, on a free platform- Docebo-based on the level B of EAPC curriculum for physicians. Launched in October 2011, it contains 10 online modules (palliative care introduction, pain, communication, ethics, terminal care, depression, delirium, insomnia, nausea/vomiting, dyspnoea) including theory, exercises, case studies, protocols, additional reading. Each module is credited with CME points.

**Aim:** This study aims to detect weaknesses and strengths of the OPCP with regard to pedagogic and technological aspects.

**Method:** Retrospective study, based on the content analysis of the all the application forms and final module assessments.

**Results:** 206 participants enrolled in the program: 103 finalised the chosen module, 25 failed the examination, 15 did not access the material at all, 63 are in the training. GPs were the largest group (45.6%) enrolled. The most requested module was the pain module (45.6%), followed by palliative care introduction (16.5%). Useful parts of the course were: exercises and case studies, referrals to specialised literature, clinical protocols and legal aspects. Informational content was appreciated as very good (100%) and new (99%), methods and materials excellent (51%) and very good (36.1%). Suggestions for the improvement of the program were: more practical examples, case studies related to patients' ages, the final evaluation test to allow participants to check the correctness of the answers, application available on mobile phone.

**Conclusion:** There was raised interest from GPs and for pain management training. The program requires an improvement regarding the software and evaluation method. The quality of information, material and methods, was appreciated as very good and excellent and interactive methods build in the modules were appreciated.

Abstract number: P1-253

Abstract type: Poster

## A Bridge to the Community

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**Aim:** The aim of the project is to provide state-wide access to two collaborative education programs in New South Wales.

**Design:**

**Vocational training for care workers:** To meet the care needs of people near the end of life a programme has been developed and implemented by HammondCare through the HammondCare Registered Training Organisation and will be available in all participating Local Health Districts. This includes training in care principles and ethics of palliative care; pain and symptom management both in end-stage cancer and end-stage chronic 'benign' disease; communication; understanding loss and grief; and self-care for the palliative care worker.

**Palliative care training for health professionals:** Continuing professional interactive education in palliative care is available throughout New South Wales using real-time videoconferencing, recorded materials (including vodcasts and podcasts), and printed materials with recognition of time spent in learning for professional registration purposes. The material for this education has been developed by HammondCare's Learning and Research Centre in Palliative Care in consultation with consortium members, Sacred Heart

and Calvary.

**Results:** A series of educational opportunities has been created to meet the needs of all practitioners in end of life care throughout the state.

**Conclusion:** We have created a successful and interactive education programme that meets the needs of health professionals across the state which will continue to grow and offer opportunities as the programme develops.

Abstract number: P1-254

Abstract type: Poster

## e-Learning, We-Learning, I-Learning: A National Forum for Palliative Medicine Undergraduate Medical Education

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**Background:** In the UK, newly qualified doctors will look after forty dying people in their first year after qualification. How can medical students be prepared to provide the best possible care for dying people and those in the last year of life? Undergraduate Medical Education is one of three Special Interest Forums (SIF) of The Association for Palliative Medicine. Its mandate was renewed in 2012. The SIF has a coordinating forum executive which lobbies and supports the membership through annual conferences with biennial themes of research and practice and an on-line resource.

**Aims:**

To describe and disseminate the methodology of a national SIF for Palliative Medicine Undergraduate Medical Education practice and research

To quantitatively and qualitatively describe the impact of a national forum in distilling and implementing excellence in Palliative Medicine undergraduate medical education practice and research

**Methods:** Delegates at the second annual conference completed a pre-post evaluation which included self-rating statements about knowledge of undergraduate curricula and research methods in educational assessment. Open comments on the impact of the conference were sought. Numerical ratings were analysed descriptively, submitted comments thematically analysed.

**Results:** 30 of 52 delegates (response rate 58%) submitted evaluations. There was positive shift in delegates self-rating in all five statements. Key themes included appreciation of shared practice, benefit of multiple teaching methodologies and future collaboration.

**Conclusion:** The SIF has run two national conferences, developed a website of teaching methods and updated a national curriculum influenced by the EAPC curriculum and supporting national medical guidance. The SIF has showed a sustained collaborative approach to developing resources and networks to support improvement in undergraduate medical education. Future aims include further synergy between teaching research and education programme delivery.

Abstract number: P1-255

Abstract type: Poster

## Palliative Care at a Danish University Hospital, a Network for Nurses in Palliative Care

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**Background:** In Denmark, 55 % die at hospital. It is necessary for professionals at the basic level to have adequate knowledge of and education in palliative care. Knowledge is lacking on whether a network for nurses within the field of palliation can ensure implementation and optimisation of palliative care.

**Purpose:** To investigate if a formally established network of nurses at Aarhus University Hospital in Denmark consisting of key persons in palliative care across departments and in collaboration with a specialist team can increase perceptions among professionals and departments of own competences within palliative care.

**Method:** A questionnaire study was conducted among all department managements, immediate superiors and key persons. The questionnaire to department managements included questions on framework for and content of palliative care; questionnaires to immediate superiors and key persons included evaluation questions on continued competence development and clinical effect.

**Results:** A total of 94 % of the department managements acknowledged that palliative care is an important task for the department. It was considered beneficial to have a key person in palliation at the department. The evaluation showed a positive effect on continuous development of professional competences in key persons, on involvement of interdisciplinary and cross-sectorial collaboration as well as on the overall knowledge of palliative care at the department.

**Conclusion:** A formally established network supported by the management has strengthened the role of key persons and the ability of departments to manage palliative challenges.

Collaboration between professionals at the basic and specialised level is considered important in the professional development of palliative care in individuals and in the organisation. Further development of palliation as an interdisciplinary area at the basic level is needed.

# Poster Sessions (Poster Exhibition Set 1)

**Abstract number:** P1-256

**Abstract type:** Poster

## People with Intellectual Disabilities: Promoting Quality End of Life Care

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**Background:** Internationally concerns have been highlighted about the quality of palliative care that people with intellectual disability receive. It has also been evidenced that people with intellectual disabilities are seldom referred to hospice and palliative care services.

**Aim:** This study aimed to explore the experience of health and social care professionals in providing palliative care to people with intellectual disabilities.

**Methods:** An exploratory, qualitative design was used. A purposive sample of thirty health and social care professionals, working in intellectual disability and palliative care services, who had provided end-of-life care to adults with intellectual disabilities, were recruited to the study following informed consent. They were asked to reflect on a case scenario of a person with intellectual disability to whom they had provided end of life care. A semi-structured interview technique, developed from the literature with open questions and prompts, was used to explore their experiences and insights. The narratives from the case scenarios were content analysed using a recognised framework.

**Results:** Three themes emerged from the data within the case scenarios: Identifying end of life care needs, meeting support needs and empowerment in partnership. Examples of good practice and issues in practice were apparent.

**Conclusion / Discussion:** This study contributes to the developing international evidence base to enhance end of life care for people with intellectual disabilities and provides further insights into this area of practice.

**Funder:** HSC Research and Development Doctoral Fellowship Scheme

**Abstract number:** P1-257

**Abstract type:** Poster

## Palliative Care Module at Undergraduate Level of Education - Evaluation of Implementing the Unitary Curricula in One Nursing Technical College in Bucharest, Romania

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**Context:** In 2007 it has become mandatory the inclusion of the Palliative Care (PC) module in the basic training for nurses at the public and private Nursing Technical Colleges in Romania. After the publishing in 2010 of, The Trainers' Manual in Palliative Care at basic level of education for nurses, the manual was voluntary adopted at national level as training resource and trainers from PC services were involved in teaching the PC module.

**Aim:** To evaluate the implementation of the Manual content in one Nursing Technical College in Bucharest, Romania.

**Method:** a prospective study, conducted between April 1st and July 21st 2014, among 157 nursing students. The data collection was realised based on the students' results at the pre and post tests and the evaluation of the PC module questionnaire. The knowledge in PC was evaluated throughout the 28 questions in the pre and post tests. The evaluation of the PC module questionnaire has 10 questions: 8 open questions and 2 Likert scale answers.

**Results:** At the end of the module, 100% of students proved increase knowledge in PC, in all 5 domains evaluated at pre and post tests: hospice philosophy and PC definition, pain control, symptom management, team work, holistic care. The PC module evaluation questionnaire shows that respondents appreciated: 100% as excellent the content of the module, 85% as a very important module for their future clinical practice, 87% as very important the fact that the module was thought by a clinical specialist in PC, 74% as very interactive the teaching methods used, 81% the length of the module as being appropriated.

**Conclusions:** This is a first initiative in evaluating the implementation of the PC unitary curricula in nursing schools in Romania. It has been demonstrated the effectiveness of the implementation of the module in regard to enhancing the students knowledge in PC and the structure of the module.

**Abstract number:** P1-258

**Abstract type:** Poster

## Palliative Care - On Becoming a Specialty for Nurses in Romania

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**Background:** Since the beginning of Palliative Care (PC) services in Romania in 1992, the pioneering organisation has in the mission to educate the interdisciplinary team members at specialist level. In 1999, PC was recognised as a specialty for physicians and multiple attempts were made to recognise PC specialty for nurses.

**Context:** The development of the PC nursing specialty program in Romania started with competencies development by an international expert panel, followed by the testing of the competencies among nurses in PC services.

**Aim:** To ensure adequate, consistent and quality training in PC for nurses in Romania, through the design of the specialised program in PC nursing based on the EAPC's standards.

**Method:** Research, translation and adaptation to internal legal context of relevant resources; weekly working group meetings of nursing PC trainers for one year; internal and external audit to agree on topics, objectives and format of the curriculum; every three months advocacy meetings with decisional professional authorities.

**Results:** EAPC nursing curricula for specialised level was chosen as base for developing the curriculum and adapted to the national legal framework for running specialised programs for nurses. A total number of 850 hours are covered in: 210 hours (25%) of theory (6 residential courses: 5 common modules and 1 module at the choice of the participant from pediatrics, management/leadership and education/research) and 640 hours (75%) of clinical practice, 4 out of the total 16 weeks being mandatory displayed in the pioneering PC service. The

National Order for Registered Nurses - Romanian professional body, adopted for proposal to the Ministry of Health, the inclusion of PC on the list of specialties.

**Conclusions:** This is a big step to ensure proper specialised education for palliative care nurses in Romania. The first cohort of the specialty program in PC for nurses in Romania is expected to start running in 2015.

**Abstract number:** P1-259

**Abstract type:** Poster

## Nursing Excellence for Underserved Population in Romania

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**Context:** Nursing education in Palliative Care (PC) in Romania became a matter of high interest over the past few years, both at undergraduate and postgraduate level. Nurses are confronted in their practice with palliative and end-of-life care issues: communicating with patients and families, educating patients with regards to diet and disease progression, stoma care and lymph edema, specific nursing techniques, administering the opioid medication, preventing and management of pressure sores, caring for malignant wounds.

**Aim:** To address gaps in the current care of cancer patients in advanced and terminal stages, particularly of those living in remote or isolated communities, by empowering community nurses with the basic and intermediate palliative care knowledge.

**Method:** EAPC nursing curricula for introductory (A) and advanced (B) level, together with the ELNEC International Curriculum were chosen as base for developing the curriculum and adapting corresponding Palliative Nursing (PN) professional competencies. A quantitative prospective study was conducted between October 1st, 2012 and September 30th, 2014 to monitor knowledge acquisition during the training by using a pre and post tests.

**Results:** In 24 months of the project a total number of 2752 professionals have been trained in the field: 219 specialised care givers, 1064 nurses (A), 1163 nursing students (A) and 306 nurses (B). The courses have been held in 30 different location in the country, 20% from rural areas and 80% from urban areas. The knowledge gained at the courses enhanced from an average of 6.06 to 8.87 points. Correlations with different variables show a medium of 3 points in between the tests.

**Conclusions:** This project ensured provision of Palliative Care training and support of nurses towards gaining the abilities and knowledge specific to basic palliative care. It has also empowered family and community carers with basic abilities for supporting patients in their homes.

**Abstract number:** P1-260

**Abstract type:** Poster

## Building Bridges to Learning in Hospices. It's Not all about Classrooms

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**Aims:** To ensure a variety of learning opportunities are available to hospice staff, enabling them to authenticate their competence to deliver compassionate, person-centred care.

Experienced nurses, with an interest in a particular aspect of clinical practice (Link nurses), develop their own knowledge and a range of learning resources to support their colleagues.

**Approach:** Registered practitioners must be autonomous, and are personally accountable for ensuring that their practice is evidence-based; a link nurse system supports this concept. British hospice staff are encountering more complex patients. Treatments for life-limiting illnesses result in greater longevity and multiple co-morbidities. The hospice patient demographic has widened to include people with non-cancer conditions; nurses must learn continually. Ageing experienced hospice nurses, retire, leaving an absence of suitable role models to support learning in practice.

Attending classroom-based teaching is not a guarantee of learning. Link nurses were supported to extend their knowledge, using self-directed learning, practice placements, e-learning, liaison with specialist practitioners, clinical audit - designing new protocols to enhance person-centred care and learning. Their presence in practice ensures that their colleagues see them as credible resources for learning.

**Results:** Link nurses learn about their subject, gather learning resources, teach and assess their colleagues, recognising the value of work-based learning. Learning from clinical colleagues leads to greater engagement in changes in practice. With support from the education team, some nurses show great commitment in developing and sharing their own knowledge to enhance care for an ever increasing population of people with complex life limiting illnesses.

**Conclusion:** Learning in practice, using link nurses, successfully shifts the emphasis away from formal teaching. Learning in hospices is not all about classrooms!

**Abstract number:** P1-261

**Abstract type:** Poster

## Compassion Awareness Education - A Collaborative Venture

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**Aim:** To raise awareness of the need for compassion and safe practice in all aspects of health care, using a collaborative approach across three UK counties. Following the identification of widespread flaws in care, nine hospices in Kent, Surrey and Sussex were commissioned to provide compassion awareness sessions to National Health Service (NHS) and social care staff in a variety of settings.

**Design:** Nine voluntary sector hospices in South East England often work together on education projects. Renowned expertise and specialist knowledge was used to design and

teach compassion awareness education over a year long project. Identical half-day sessions using evidence-based theories, included experiential learning and introduced action planning to embed learning in practice.

The participants worked in a range of roles in health and social care, and will disseminate their learning to colleagues. The half day programme includes guidance on sustaining compassionate practice in the workplace. A customised three-point evaluation process is integral to the project.

**Results:** In the first two months of the project, 325 staff from a range of professions employed in diverse organisations attended. Participants reported increased levels of confidence in delivering compassionate care following the education sessions. Post session surveys indicate that many participants used their action plans in practice. This project has enabled local practitioners to establish and strengthen relationships with local hospices.

**Conclusion:** A collaborative approach to design and present compassion awareness education was used across three counties. Hospice educators, with their expertise in facilitating learning, encouraged health and social care staff to consider and reflect upon compassionate practice. The use of an action plan within the education sessions supported participants to engage more deeply with the concepts of compassionate care and how to foster it in themselves and others.

**Abstract number:** P1-262

**Abstract type:** Poster

## The Training Evaluations of the End-of Life Care Facilitators (EOLF) Educational Program for Nurses that Practice Advance Care Planning (ACP) in Japan

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**Background:** The need for Advance Care Planning (ACP) in Japan is attributed to the increase in elderly people who wish to live independently as long as possible. ACP is the process in which patients, their families and medical experts collaborate towards common goals of treatment/care. Not only does ACP improve end-of-life care, it also enables elderly people to live an autonomous and dignified life in accordance with their wishes. Therefore ACP is implemented for terminal-stage patients as well as healthy elderly people. Furthermore, ACP should be facilitated by nurses for it to be effective.

**Aim:** This study aims to understand the concept of ACP and create a training program for nurses in facilitating ACP for elderly people with chronic illness. This paper describes participant's evaluation of the program by pre and post-test, and participant's reflection sheets.

**Methods:** The subject comprised nurses interested in implementing ACP. The training program combining a lecture and group discussion was a one-day course held in four times between December 2014 and March 2015. An evaluation of the course was conducted by questionnaire after completion of the course.

**Results:** The 40 nurses who participated the course. The course was effective with 94% of the participants answered that 'the training is meaningful' and 92% that they 'would like to apply the training'. The desire to implement ACP was describe in the free comments section with 'I hope to keep the sense of values and life history of the elderly in mind when communicating' and 'I'd like to work out a way of life with both the patient and their family members'. However it was pointed out that the training should be on-going with comments like 'I'd like to improve my skills further'. In future, on-going training to improve skills as an ACP facilitator should be investigated, and nurses able apply ACP to healthy elderly people should be trained.

**Abstract number:** P1-263

**Abstract type:** Poster

## End-of-Life Care in Japan: Semi-structured Interviews with Junior Family Doctors

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**Background:** There is an increasing need for family doctors to be involved in end-of-life care in the community due to ageing population. Although it has been reported that family doctors experience various difficulties in end-of-life care, there is little evidence from Japan. To promote their involvement in end-of-life care, we need to clarify difficulties they experience.

**Aims:** To explore the experience of junior family doctors caring of the dying at home and to identify difficulties and conflicts in learning how to provide care.

**Methods:** A qualitative study with semi-structured individual interviews with 12 family doctors was conducted. Interviews were designed to explore difficulties in end-of-life care at home. The transcripts of the interviews were analysed combining qualitative data analysis and theoretical coding.

**Results:** Participants were aged from 29 to 35 with from 4 months to 5 years of experience in home care. Several categories were identified by the analysis; prognostication and truth telling; 'family care', 'the art and skills in care for the dying' and 'learning how to provide the care'. Participants find it difficult to estimate the trajectories and to tell the truth. They feel difficulty in death education for families, compassionate approach and understanding family's feelings. They also see end-of-life care at home as a ceremony of collaborative work with family, and feel uncomfortable with formal death declaration. These difficulties and conflicts are increased when they do not have supervision. They regard learning end-of-life care as learning without role models and difficult to make explicit. They value learning from nurses.

**Conclusion:** Junior family doctors experience various difficulties and conflicts in end-of-life care for patients at home. It is important to have reflective discussions with educators including other professionals such as nurses and palliative care specialists. The study was funded by Tokyo Hokenkai.

**Abstract number:** P1-264

**Abstract type:** Poster

## Factual Investigation of Undergraduate Education in Palliative Care at Pharmaceutical Colleges and Pharmaceutical Departments around the Country in Japan

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**Background:** Pharmaceutical undergraduate education in Japanese universities changed from a 4-year course to a 6-year course from 2006, and from 2012 graduates who have received the new education have been clinically active. In Japan, each university individually sets curriculum in compliance with the Pharmaceutics Model Core Curriculum. In recent years, the number of lectures in clinical fields has drastically increased, and the contents are also becoming richer, but it is known that there are large differences between the universities.

**Aim:** Considering this, this academic society decided to conduct a survey of the current situation in order to assure the quality of pre-graduate education in palliative care in Japan.

**Method:** We sent questionnaires to university presidents, deans, and concerned teaching staff at 74 public and private universities around the country and collected the answers via FAX. The questionnaires consisted of 14 items including 'Is palliative care necessary in pharmaceutical education?', 'State of implementation of palliative care education', 'Influence on pharmacists' duties', and 'Sense of satisfaction in lectures'.

**Results:** The response rate to the questionnaire was 71.6%, or 53 of the 74 schools. 96% responded 'Yes' to 'Is palliative care necessary in pharmaceutical education?' 86.5% responded 'Yes' to 'Do you conduct lectures regarding palliative care?' As for the number of classes of the lectures, 58.7% responded 2-7, which was the highest, and 6.5% of universities had 17 classes or more. 52.8% responded 'No' to 'Is the current state of palliative care education sufficient?'

**Considerations:** This investigation showed that the necessity of palliative care was recognised at most universities and that lectures devised at each university are being conducted. However, because about half of universities feel that it is currently insufficient, we can expect that education in this field will be further enriched in the future.

**Abstract number:** P1-265

**Abstract type:** Poster

## Evaluation of a Mental Health Program for Palliative Care Health Care Workers

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**Background:** Health care workers who are engaged in palliative care face the patient's death and the grief of the family on a daily basis. Because they are constantly in a stressful situation, mental care for them as well as for the patients and family is important. They likely need some kind of support from a mental health program.

**Aims:** We have created such a program that incorporates both the opinions of health care workers and information from the published literature, and then we evaluated its utility.

**Methods:** The workshop using our program involved the participation of 16 nurses. The program was well received. Then, we modified the program incorporating the opinions of both the participants and facilitators.

**Results:** The program contains three-parts, and each part is configured to last approximately one hour. The three parts also can be scheduled together requiring about three hours. The program is flexible and can be modified according to the workplace situation. In the first part, the significant event analysis is performed in groups of four participants. All members debate the mental problems supportively. A facilitator placed in each group moderates the debate. In the second part, lectures are presented on 20 items of specific measures of self-care and the group work is performed intermittently. For example, some of the topics include, 'Methods of assertion for conflict with other occupations' and 'Value of palliative care work'. In the third part, using the World Café format, the participants each share their self-care methods. Then they debate and create a useful self-care strategy.

**Conclusion:** Mental health programs should be easy to access, easy to use, and adaptable to each workplace environment. In the opinion of the participants of this study, our program is easy to use. It will be necessary to revise repeatedly and continue to improve the program in the future by incorporating the opinions of both the participants and facilitators.

**Abstract number:** P1-266

**Abstract type:** Poster

## EAPC Enquiry on Spiritual Care Education

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**Background:** The White Paper on Palliative Care Education states that in order to benefit patients and their families, all palliative care professionals should be able to open dialogue about meaning, purpose and change - central points in any discussion of spirituality and spiritual needs. The confidence to assess needs and meet appropriate outcomes will only be achieved through relevant training programs.

**Aims and methods:** In October 2013, an online enquiry was launched by the Education subgroup of the EAPC Spiritual care Taskforce among EAPC members. The enquiry was designed to capture all those courses running presently, or planned for the near future, which would interest professionals and volunteers to develop skills and improve practice.

**Results:** We received 36 responses of which 78% (n=28) derive from Europe. The enquiry revealed that 81% (n=29) of training programmes use the EAPC working definition of spirituality. 64% (n=21) of training is provided to all health care professionals, profession-specific training is less common. 85% (n=28) of training is provided face to face in a classroom setting. The highest priorities within training are: reflective listening and communication (86%, n=31), individual awareness and self-handling (78%, n=28), and



providing support in spiritual crises (75%, n=27). Performance assessment is often disregarded in favour of course evaluations (32%, n=15).

**Conclusions:** The enquiry raised some pertinent issues for all educationalists and practitioners. Firstly, the use of a single definition of spirituality would help all healthcare staff to work with a uniform means of spirituality. Secondly, evaluations are important and provide a means to critically appraise the training delivered. However, of more help in developing spiritual care competencies are the use of reflective practices and performance assessment. Thirdly, setting spiritual care into the context of broader courses enables this core skill to be embedded in palliative care.

**Abstract number:** P1-267

**Abstract type:** Poster

## Dying in Social Media: Effectiveness of Social Media versus Classroom Based Education in Palliative and End-of-Life Care Topics among Undergraduate Nursing Students

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**Background:** Online social networks act as a mode of communication that helps to share information and resources and collaborate with peers through engaging in social media based digital dialogues. Yet, little evidences exist on the use social media in healthcare professionals' education; particularly in palliative and end of life care education.

**Aim:** To explore the effectiveness of social media and classroom based end of life care education among undergraduate nursing students in one UK Higher Education setting.

**Methods:** A qualitative participatory approach was adopted. In total of 196 first year undergraduate nursing students were invited. 157 students joined Facebook based teaching and 34 students attended classroom-based end-of-life care teaching that delivered similar learning objectives. Multiple data were collected; student run two focus groups (n=12 students), feedback through Facebook messenger (n=23), in-session Facebook feeds (n=2803) and email feedback responses (n=8). Using Nivio10<sup>®</sup>, a thematic analysis was undertaken.

**Results:** A comparative analysis between social media versus classroom based education resulted in five themes that explored its effectiveness in teaching palliative and end-of-life care topics among nursing students: speaking out, lecture at living room, technology lessens interest, emotional teaching, and re-live lesson.

**Conclusions:** Our study explored that using social media in death dying education enhances students' learning experiences both in emotional as well as knowledge acquisition similar to classroom teaching. However, Facebook teaching provided more flexibility and increased interest yet attained similar learning outcomes.

**Abstract number:** P1-268

**Abstract type:** Poster

## Using Collaboration and Innovation Across Continents to Provide Palliative Care Education

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**Introduction:** Delivering effective palliative care to patients and families requires education for all healthcare workers. Accessing education is challenging in terms of time, cost and manpower, particularly in resource poor settings. Using technology for education is not a universal concept: the most usual concern is lack of internet availability. Technology and massive open online courses (MOOC's) continue to develop however. We report on a project successfully using collaboration between organisations in Africa and UK to produce 20' open access' e-learning modules on palliative care topics.

**Methodology:** Each module comprises interactive quizzes, reflective practice, facts presented as film clips and slides and ends with future learning prompts, resources and evaluation. The film clips are of interviews and teaching in UK and Africa. An evaluation form seeks satisfaction scores and free text comments on expected change in professional practice.

**Results:** Out of 256 participants, 38 (15%) requested a text version. All modules have been accessed; the most popular: principles of palliative care (14%), respiratory symptoms (8%), fatigue/weakness and nausea and vomiting (both 7%). 71% participants strongly agreed that the modules were easy to navigate, 76% that the course design made the subject matter interesting, 97% agreed (69% strongly) that the course would help them perform their job better. 71% accessed the material at home, 29% at work. Free text reflected increased awareness of basic principles: pain assessment, symptom assessment frameworks, opioid doses, spiritual care and communication skills. Feedback on content and production such as shorter video clips and more patient stories is informing future applications of the project.

**Conclusion:** Creating effective e-learning material provides opportunity for effective collaboration and innovation. Ensuring educational quality and continuing to evaluate the impact on patient care remain priorities.

**Funding support:** IAEA

**Abstract number:** P1-269

**Abstract type:** Poster

## A Collaborative Learning Process to Improve Awareness and Knowledge of Palliative Care at Different Care Settings

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**Background, aims and goals:** In Sweden, palliative care is provided across a variety of care settings by a range of different professions. A national survey conclude that the basic education in palliative care for health care professionals vary considerably. The Centre for

Collaborative Palliative Care is cooperation between a university, the county council and eight communities. The main goal of the Centre is to conduct education in palliative care for professionals and to integrate the new knowledge in clinical practice simultaneously. The aim of the presentation is to describe this educational effort.

**Design, method, and approach:** The education has been developed in collaboration with patients, family members, managers and staff from the communities, the county council and the university. An education material was developed from their knowledge and experience, the National Clinical Practice Guidelines for Palliative Care and relevant literature. The material includes six themes (a palliative approach, care with dignity, symptom relief, existence and dying, family members, and collaborative care) as short texts, questions for reflections and suggestions for further studying. The participants are also asked to bring experiences from their clinical work and to bring back ideas for clinical improvement. In groups of 8-12, mixed professionals meet 2-3 hours, 6-8 times during one year to work with the themes together with representatives from the Centre.

**Results and conclusion:** The project is ongoing and so far approximately 100 professionals at eight different care settings have participated in the education. Preliminary evaluations show great satisfaction and several quality improvement projects have been proposed by the professionals. The education also seems to be an adequate method to implement National Clinical Practice Guidelines for Palliative Care. A comprehensive result will be presented at the conference.

**Funding:** The Kamprad Family Foundation

**Abstract number:** P1-270

**Abstract type:** Poster

## Impact of the Nordic Specialist Course on the Development of Palliative Medicine in the Nordic Countries. A Survey among 150 Participants from Five Courses during 2003-2013

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**Background:** The five nordic associations for Palliative Medicine (PM) have since 2003 organized a theoretical specialist training course consisting of 6 week-long modules over 2 years. All major topics in PM are covered. Participants must attend the modules, complete a limited research project, hand in a written assignment after each module and pass the final exam in order to receive the diploma. Up to now 150 physicians have participated in five courses.

**Aim:** To examine what impact this educational program has on participants and the field of PM.

**Methods:** An ad-hoc electronic questionnaire was sent out to the physicians who had completed a course in 2003-2013 (n=150). Questions covered demographic information (n=4), pre-course information on medical education, specialty and working place (n=3) and post-course information regarding current work and activities to promote PM (n=12).

**Results:** Response rate was 84% (n=126, 36% men and 64% women). General practice, internal medicine, anesthesiology and oncology were the most common specialties. Before the course 45% worked in a local/regional hospital, 35% in a university hospital and 20% in primary care. Over 90% received the course diploma. After the course 70% had attended one or more PC conferences, 26% had presented an abstract from the course project at a conference and 13% published a paper in a peer-reviewed journal. Around 84% are currently working in a clinical PC setting, 56% as leaders. Over 90% teach PM, 41% participate in developing national guidelines, 49% are active in a national PM association and 39% take part in lobbying activities.

**Conclusion:** The Nordic Specialist Course in Palliative Medicine has a profound impact on participants' post-course career and most are now working within PM as leaders, teachers and activists. PM will be approved as a formal competence field in all the Nordic countries during 2015. The Nordic course, or a comparable course, will be required for the theoretical part.

**Abstract number:** P1-271

**Abstract type:** Poster

## GSF Improving End of Life Care in Community Hospitals

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**Background:** Many elderly people in rural areas of the UK nearing the end of their lives are cared for by Community Hospitals, which are often small GP or geriatrician-led units. GSF service improvement/training programmes are used extensively in the UK and we report on the first round of Accredited Community Hospitals. Evidence suggests that 30% acute hospital patients are in the final year of life but the figure in community hospitals is likely to be higher, though never previously measured.

**Aims:** The study examines progress since the introduction of GSF Community Hospitals Programme in 42 Community Hospitals and the first 12 Cornish Community Hospital wards that received the GSF Quality Hallmark Award.

**Method:** The 12-18 month programme is delivered through interactive workshops, based on the well-used GSF programmes in other areas and using the GSF intrinsic evaluations. The robust evaluation includes

- Key outcome ratios - evidence of measurable change before and after training intervention
  - Audit
    - a) Patient level - After Death Analysis sample
    - b) Staff confidence
    - c) Organisational changes
    - d) Qualitative Patient/carer/staff feedback
- Hospital wards can then progress to accreditation with a portfolio of evidence and assessment visit.

**Results:**

- § Staff are identifying patients thought to be in their last year of life earlier, with an average of 37% identified
- § A systematic plan is introduced including needs-based coding, GSF Core Care Plans etc



§ More were offered Advance Care Planning discussions  
§ Ward teams showed improved communication with others, especially with GPs  
§ Staff confidence improved and there was a greater cultural openness in discussing dying.  
**Conclusion:** GSF Quality Improvement Programme for Community Hospitals has helped improve the quality of end of life care in rural areas, and enable more to live and die well as they would wish.  
No previous programme had assessed this or shown significant improvements, especially in early identification.

**Abstract number:** P1-272  
**Abstract type:** Poster

## Does Medical School Prepare for Strong Opioid Prescribing in the Real World?: The Experience of Junior Doctors at a District General Hospital in the United Kingdom

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**Background:** Opioid prescribing is a fundamental competence of doctors. Confusion and uncertainty, however, regarding initiation, titration and side effects are not uncommon. Undergraduate medical education should lay the foundations for safe and effective prescribing of opioids including accurate assessment of dosage and likely side effects.  
**Method:** A written questionnaire exploring the knowledge and attitudes toward opioid prescribing was distributed to cohorts of junior doctors from foundation year one (FY1), foundation year two (FY2) and core medical training (CMT), working at a district general hospital in the UK. Questions were taken from the implementation tool accompanying national guidance on opioid prescribing. Correct answers were scored one point and the maximum score was 20.  
**Results:** 10 FY1, 10 FY2 and 10 CMT doctors responded. Mean scores from each cohort were 10.30, 14.95, and 13.15 respectively. Five FY1 doctors cited sedation, addiction/dependence, and quicker death among fears of opioid prescribing. Only four FY1 doctors attempted to perform a simple drug calculation and none of their answers were correct.  
**Discussion:** Lack of knowledge of correct opioid prescribing produces a risk of unsafe practice. However, prior formal education on this subject was perhaps brief and largely at undergraduate level. There was a theme of misconception regarding the safety profile of appropriately prescribed opioids; this may have arisen from a focus on rare but important safety issues. While all cohorts did not score highly, on average FY1 doctors answered most questions incorrectly. This is concerning and could lead to patient harm.  
**Conclusions:** We suggest undergraduate medical education may not be preparing doctors for safe initiation, continuation and monitoring of strong opioids. Undergraduate education needs to address basic controlled drug prescribing in order to produce doctors who are able to safely and effectively prescribe opioid medication.

**Abstract number:** P1-273  
**Abstract type:** Poster

## Development, Implementation, and Assessment of a Palliative and Hospice Care Online Module and Clinical Experience for Second-year Medical Students

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**Background:** In order to prepare medical students for bedside learning in the care of patients with terminal and advanced illness, education in the principles and practices of palliative and hospice medicine is best initiated in the pre-clinical years. Online tools have been shown to be an effective, flexible method in diverse areas of medical education.  
**Aims:** To explore the application of an online learning tool in conjunction with a hospice clinical experience in the educating medical students, a 30-minute interactive online module was created with the following learning objectives:  
• To articulate the qualifications for and the services provided by hospice care  
• To recognise the stages of active dying and identify the accompanying physiological changes  
• To list five common end-of-life symptoms and differentiate their pharmacological and non-pharmacological treatment options  
**Methods:** The online module was piloted with 112 second-year medical students in 2012 and 2013. Students were randomly assigned to the complete the online module or not (control group) prior attending the required half-day hospice clinical experience. Students in both groups then completed a knowledge- and attitude-assessing questionnaire.  
**Results:** Students who completed the online module prior to the hospice experience scored higher on multiple choice questions pertaining to hospice and palliative care ( $p < 0.05$ , two-way ANOVA) but their attitudes were similar to those who did not complete the online module. Overall, the students felt somewhat uncomfortable caring for dying patients even though they regard it as a physician's duty, and that palliative/hospice care education is important in medical school.  
**Discussion:** When combined with a mentored clinical hospice experience, an online module appears to enhance teaching of the dying process and terminal care to pre-clinical medical students. A new online learning module may prove useful to integrate in curricula in other institutions.

**Abstract number:** P1-274  
**Abstract type:** Poster

## A Survey of Cancer Pain Management Knowledge and Attitudes of Northwest Bulgarian Physicians

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**Introduction:** A survey amongst physicians from Northwest Bulgaria was conducted as a part of a bigger project on epidemiology of cancer pain, its control and potential barriers to its management. The main target was to reveal their knowledge and attitudes towards cancer pain management, the use of opioids for control and effects of opioid regulation on their prescribing practices.  
**Methods:** A questionnaire survey based on the similar survey from Canada was delivered to physicians from Northwest Bulgaria. It assessed their basic knowledge and attitudes towards cancer pain management and opioids prescribing and also collected demographic data.  
**Results:** Using the Regional office of Bulgarian Medical Association database 250 practicing physicians were contacted by email. 149 questionnaires were returned (60% response rate). Oncologists and ER physicians achieved highest knowledge score and had less concern about regulation restrictions. On the other side were surgeons and GPs from small towns. Most concerned about opioid regulations were those from small towns and rural area and those with > 30 years of practice. Most 'don't know' answers were given to the questions about equianalgesics dosing (35%) and breakthrough pain dosing (30%). The highest percentages of wrong answers were given to questions about addiction - 'the risk of addiction in any patient on opioid is 25% higher' - 51% 'physical dependence is a sign for addiction' - 62% and 'Patients who complain of disproportionate pain are drug abusers' - 56%. The most confusing answer given by almost 60% (77) was that 'placebo is a useful test to determine the reality of patient's pain'.  
**Conclusion:** The results of the survey reveal insufficient knowledge of the physicians of Northwest Bulgaria about cancer pain and its treatment. There are also concerns about regulation especially among older physicians and those practicing in smaller settlements, which is a big barrier to adequate cancer pain control.

**Abstract number:** P1-275  
**Abstract type:** Poster

## Identifying Palliative Care Domains relevant to Emergency Medicine Resident Training: Literature Review and Expert Consensus

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**Aims:** Hospice and Palliative Medicine is a sub-specialty of Emergency Medicine (EM). EM trainees routinely care for patients with serious life-limiting illness. However, no defined palliative care (PC) curricula for EM resident training exist. The objective was to identify PC domains and topics that are relevant to EM training through literature review and expert consensus. The ultimate goal is to design a EM-PC resident curriculum for the US.  
**Methods:** Clinical practice guidelines review and a comprehensive search of MEDLINE, CINAHL, ERIC, PsycINFO, and SCOPUS was completed for published studies using the terms: palliative medicine, hospice, palliative care, emergency medicine, topics, education, and training. Citation search and abstract review by 2 independent reviewers yielded 4 studies from 47. Manuscript analysis revealed recurring topics for EM-PC in 3 domains. An expert panel was convened from the American College of Emergency Physicians' Palliative Section with members added for expertise. Members included EM faculty, residents and nurses with expertise in curricular design, PC, EM residency and PC fellowship leaders and faculty with dual EM and PC board certification. The panel reviewed topics, assessed content for validity and importance to EM training, and finalised topic language.  
**Results:** Topics relevant to EM-PC training in 3 main domains (with 23 sub-topics) were identified:  
1) Provider skill set (e.g., management of chronic pain/distressing symptoms, difficult communication, goals of care;  
2) Clinical recognition (e.g., rapid PC assessment, prognostication);  
3) Logistical understanding (transitions across care settings, multidisciplinary team/support systems).  
**Conclusion:** Key PC topics and domains relevant to EM resident training were identified. These are being mapped to develop competencies and milestones for the EM-PC resident education curriculum. Next steps include using the Delphi method to validate and develop a final topic list.

## Ethics

**Abstract number:** P1-276  
**Abstract type:** Poster

### GPs and EoL Care - Views and Experiences

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**Background:** Few, if any, studies have been carried out on the topic.

**Aim:** To better understand and describe this aspect of care.

**Methodology:** A national validated survey was mailed to all GPs of the country.

**Results:** The response rate was 44%. 28.7% of GPs received no formal training in palliative medicine and had been practicing for 23.76 years (95% CI: 21.68 - 25.84). 89.8% of respondents declared that their religion was important in EoL care. 45.3% (23.3% disagreed, 31.4% neutral) agreed with the right of a patient to decide whether or not to hasten the end of life. 51.9% agreed (30.1% disagreed, 18.1% neutral) that high quality palliative care nearly removes all requests for euthanasia. 70.5% agreed (17.7% disagreed, 11.9% neutral) that physicians should aim to preserve life.

On average, in the previous 12 months, they cared for 4.44 EoL patients (95% CI: 3.67-5.21). 15% of GPs withdrew or withheld treatment in the care of these patients. Of the remaining 85%, 24.4% agreed with such practices. 41.1% had intensified analgesia at EoL with the possibility of hastening death whilst in the remaining 58.9%, 28.5% agreed with such practices. 7.5% had sedated patients at EoL. Lastly, 89.1% GPs would never consider euthanasia.

Significant correlations ( $p < 0.05$ ) were observed between considering euthanasia, previous practice of sedation, importance of religion in decision making and patients' rights in EoL. A thematic analysis of comments highlighted the importance of the topic, 'feeling uncomfortable' in EoL care, the religious aspect of care, lack of legal framework and the challenge of symptom control.

**Conclusions:** For many GPs, religion guides choices in EoL care. There needs to be more training in palliative care. A huge majority of GPs oppose euthanasia but a good number of GPs are in favour of rationalising treatment at EoL whilst addressing the often conflicting issues of patient rights at EoL and the need to preserve life.

**Abstract number:** P1-277  
**Abstract type:** Poster

### Flemish Physicians' Labeling of Palliative or Terminal Sedation: Broader than Guideline Descriptions

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**Background:** The indications and due care requirements for palliative or terminal sedation are well-described in recommendations and guidelines. Among other things, it should not be intended at hastening death, opioids are discouraged as being ineffective, and patient and/or family should be involved in decision-making.

**Aims:** We examined the characteristics of actual end-of-life practices labeled as palliative or terminal sedation by reporting physicians in a large-scale survey in Flanders, Belgium.

**Method:** We selected a large representative sample of death certificates in 2007 ( $n=6927$ ). Attending physicians were approached by means of a postal questionnaire about end-of-life decision making and were asked to choose the most appropriate label to describe their actual practices.

**Results:** Response rate was 58.4%. In 9.6% ( $n=416$ ) of all deaths physicians performed an end-of-life practice they labeled as palliative or terminal sedation. In these cases, an explicit life-shortening intention was reported in 22%, physician-estimated life shortening was 24 hours or more in 51% and opioids were used as only drug in 51%. Neither patient nor family were consulted in 19%.

**Discussion:** In 2007 many physician-labeled palliative or terminal sedation cases lacked correspondence with description in official guidelines. Our results suggest that the concept of palliative or terminal sedation covers a broader range of practices in the minds of physicians. The resulting ambiguity is a barrier to sound end-of-life sedation practice, and implementation of practice guidelines - like the one issued in 2010 in Flanders by the Federation for Palliative Care Flanders - are necessary to clarify the concept and improve familiarity with practice requirements.

**Abstract number:** P1-278  
**Abstract type:** Poster

### Palliative Sedation (PS) at the End of Life - Revision of the Norwegian Medical Association's Guideline

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**Background:** In 1998, a palliative care physician accused a colleague of having performed illegal euthanasia on eleven patients. He denied all allegations, insisting that it was a matter of symptom control according to a procedure then called 'terminal sedation'. After police investigation, the case resulted in omission of prosecution due to insufficient evidence. Subsequently, the Norwegian Medical Association (NMA) mandated an expert panel that worked out a guideline on 'palliative sedation'. Published in 2001, it was the first of its kind in Europe.

**Aim:** To revise the 2001 NMA guideline on palliative sedation (PS) for the dying.

**Method:** In 2013, the central board of the NMA appointed a new working group. Taking into account follow-up data, released in 2006, on the practice of PS in line with the 2001 guideline, the group came up with a considerably shorter document than the one of 2001.

**Result:** The new guideline consists of a brief introduction and 12 items. The amendments are as follows:

- 1) In rare instances, isolated psychiatric symptoms may be an indication for PS (No. 2)
- 2) PS may be given to patients whose life-expectancy is beyond a few days (No. 3)
- 3) PS may be applied within primary health service, provided the required competence and resources are in place (No. 4)
- 4) Intermittently waking up the patient should always be considered, but need not always be attempted. Accordingly, a patient may be left in a state of unconsciousness until death occurs (No. 9)
- 5) When the patient takes just sips of water, there is usually no indication for parenteral fluids (No. 11)

**Conclusion:** The revised and, in 2014, approved NMA guideline on PS represents a somewhat more liberal stance on the practice. We believe it will prove a helpful tool to clinicians, enabling them to deliver the best possible care to patient with refractory symptoms. It provides a framework for treatment that is well within both ethics and law. We will present the new guideline.

**Abstract number:** P1-279  
**Abstract type:** Poster

### The Process of End-of-Life Decisions Regarding People with Intellectual Disabilities

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**Background:** End-of-life decisions are made as often for people with intellectual disabilities (IDs) as for the general population. Representatives, physicians and paid care staff are involved in the process of decision-making.

**Aims:** To study the process of end-of-life decisions and the roles and considerations which are important in the decision-making process.

**Methods:** This qualitative study, carried out in the Netherlands, involved semi-structured interviews with ID physicians, representatives of people with IDs and paid care staff. Interviews were made after the deaths of ten patients with IDs that had involved end-of-life decisions. The interviews were recorded digitally, transcribed verbatim and analysed using Grounded Theory procedures.

**Results:** Physicians involved representatives and paid care staff in the decision-making process. Physicians based their decisions on the needs, preferences and the medical life story of patients who are not (or not fully) able to decide. Physicians allocated to the representatives the capability of evaluating the quality of life of their loved one. The representatives felt highly responsible for the decisions and took into account ideas about quality of life, prevention of suffering and the ability of their loved one to understand the burden of possible interventions. The paid care staff considered themselves to be at the centre of the communication. They did feel responsible for the end-of-life care, but not for the end-of-life decisions. They were confident about their own opinion as they felt familiar with the patient's needs and preferences. Paid care staff and representatives both reported being unclear about who had the responsibility for the end-of-life decisions.

**Conclusion:** The roles and responsibilities turned out not to be quite clear, with uncertainty and conflicts arising particularly as regards evaluating the quality of life. Advance care planning and shared decision making could be useful tools to improve the process.

**Abstract number:** P1-280  
**Abstract type:** Poster

## Norms and Valuation of Medication Management in the Last Phase of Life: A Qualitative Research

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**Background:** Patients in the last phase of life are prone to polypharmacy. Literature states that medication at the end of life should be critically evaluated on its merits. Caregivers often experience medication management in this stage of life as complicated because of the interaction of medical, emotional and ethical factors. Little is known about norms and valuations of patients, relatives, nurses and physicians on medication management in end of life situations.

**Aims:** This empirical study aims to gain insight into the perspectives of involved parties on medication management in the last three months of life.

**Methods:** A multicenter study including in-depth interviews with patients, relatives, nurses, specialists and general practitioners. Analysis took place using the constant comparative method, with the aid of the software program ATLAS.

**Study population:** Eighteen patients were recruited in three university and regional hospitals, two high-care hospices, and in primary care.

**Preliminary results:** Eighty interviews with 18 patients, 14 relatives, 16 nurses, 16 specialists, and 16 general practitioners were conducted. Preliminary analyses elucidated that medication review had no priority for professionals. Patients underlined the importance of thorough medication checks and illustrated the capability to specify preferences about medication-decision-making participation. Five themes came forward:

- 1) importance of maintenance of hope,
- 2) physicians know what is best for patients,
- 3) patients should not be in pain,
- 4) patients should not use unnecessary medication,
- 5) medication reduction should be tailor made.

**Preliminary conclusions:** Although involved parties hold the opinion that patients should not use unnecessary medication, and medication management should be personalised, reviews are not matter of course. Striking were the differences between settings and professionals and the limited understanding of needs and expectations of patients on the subject.

**Abstract number:** P1-281  
**Abstract type:** Poster

## A Systematic Review of Ethical Issues in the Clinical Practice of Palliative Care

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**Background:** Continuous growth of ethical reflection in palliative care (PC) literature provides the theoretical basis and justification for clinical practice and insights on specific ethical dilemmas. Scientific literature is one of the main tools for training and updating in PC, whereas not all Schools of Medicine have specific PC programs and there is a lot of variability in ethics programs as well.

**Objective:** To systematically identify the most relevant ethical issues with reference to the clinical practice of PC.

**Methods:** Using the PRISMA systematic review method we searched Medline database, as the most comprehensive database (it includes different professions and perspectives: clinical, philosophical, social) and presumably the most widely used source for continuing education (freely available). Search strategy (from 2000 to 02 Sept 2014): ethic\* AND (palliative care [MeSH Major Topic] OR hospice care [MeSH Major Topic]) NOT student\* (filters: humans, adults, English). Exclusion criteria: paediatrics, research, teaching, no palliative care as a main setting, no ethics as a main focus. Inclusion criteria: clinical and ethical focus.

**Results:** A total of 382 articles were identified; 243 met inclusion criteria. Ninety-seven articles were published in palliative medicine journals. Sixty-two articles examined ethical aspects related to interventions and medications, 27 to non-malignant diseases; 25 to delivery of health care, 23 to spirituality, 23 to theoretical debate, 21 to decision-making, 21 to psycho-social aspects, 17 to communication, 16 to assisted suicide/euthanasia, 8 to symptoms management.

**Conclusions:** Ethical reflection in PC touches on many topics. However, in many areas it remains the call to greater education. We need more empirical research which focuses the ethical dilemmas that most affect the moral conscience of PC professionals, in order to devote more attention to these dilemmas on a theoretical reflection level.

**Abstract number:** P1-282  
**Abstract type:** Poster

## Documentation and Monitoring of Palliative Sedation in Clinical Practice in Germany

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**Background:** In 2013, a systematic overview of the current general clinical practice of palliative sedation (PS) in Germany, assessed via a questionnaire survey, has been published. Considerable differences in clinical practice between institutions were found. This investigation aims to show common core elements and rarities of in-house documents in clinical practice, and to what extent these practical attempts meet the EAPC framework recommendations.

**Methods:** In September and October 2012, Palliative Care Units, Inpatient Hospices and Specialised Outpatient (Paediatric) Palliative Care Services listed in national address registers, were invited via e-mail to participate in a national survey on the clinical practice of PS. Within this questionnaire sections on Evaluation, Documentation and Guidelines the participants were requested to upload their in-house scores, specific protocols and guidelines for the application, documentation and monitoring of PS. A systematic structured content analysis of documents was carried out with MAXQDA.

**Results:** The questionnaire was sent to 605 contact persons; response rate was 37.2%. 225 participants in summary provided 57 templates on symptom assessments, scales on sedation depth, specific monitoring documents and guidelines for PS.

Common core element in all guidelines was the description of indications for PS. Instructions on informational needs of patient's family or care for medical professionals appeared rarely. Definitions of abuse of PS expanded contents of EAPC recommendations. Scales for symptom assessment and sedation depths widely matched the EAPC recommendations.

**Conclusions:** There are significant differences in  
(1) the contents,  
(2) extent and  
(3) patterns of documentation of PS in Germany.

The findings may facilitate the development of a standardised operational guideline for clinical practice of PS. This could ease for the step-by-step application of PS in clinical practice and for comparability within research attempts.

**Abstract number:** P1-283  
**Abstract type:** Poster

## Patients' Understanding of their Dying Trajectory and their Wish to Die

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**Background:** Despite best palliative care, patients might express a wish to die. Being responsive to these wishes with attention and care requires first-person-knowledge about patients' experiences and perceptions.

**Aims:** To better understand the content and structure of wish to die-statements of palliative patients in the context of different illness narratives.

**Methods:** Qualitative interview study with 30 palliative non-cancer patients (neurological disease; organ failure; frailty), their families and health professionals. Data analysis through Interpretive Phenomenological Analysis and Grounded Theory.

**Results:** In a previous study on 30 cancer patients (116 interviews) we developed, grounded in data, a model to understand wishes to die more in detail. Three dimensions were identified that are important to understand wishes to die: Intentions, motivations and constitutive social interactions around these wishes. In the current study on non-cancer patients, we use this model to investigate whether wishes to die are experienced differently by non-cancer patients. One important new question is, in which way the subjective perception of the illness and dying trajectory is important in the experience of a wish to die. While cancer and ALS patients are often aware of the predictable course of their illness, patients with advanced organ failure or frailty see the prospect of their life in less clear terms. Based on selected cases, we show that the anticipating narratives that patients tell about their future are meaningful for understanding the patient and her/his choices in the present. Subjective expectations, that might differ significantly from objective information about dying trajectories, frame patients' decisions and current wishes.

**Conclusions:** Ideas about the patient's own dying trajectory are one important dimension for understanding patients' wishes to die. Subjective perceptions of dying trajectories might differ significantly from their objective course.

**Abstract number:** P1-284  
**Abstract type:** Poster

## Living Wills Requesting Euthanasia in Flanders, Belgium

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**Background:** In 2002, the Belgian Parliament legalised euthanasia, i.e. the use of life-ending drugs by a physician on explicit patient request. In 2007, 2% of all deaths in Flanders (Belgium) were from euthanasia. A request for euthanasia can be expressed in a living will, which is not legally binding and acts as a guide for patients' treating physicians.

**Aim:** To estimate the prevalence of living wills requesting euthanasia in a sample of deceased Belgian residents drawn from death certificates, as reported by the certifying physician, and to examine the factors associated with having such a will.

**Methods:** A random sample of 6927 cases was drawn from all death certificates in Flanders, Belgium, from June 1 through November 30, 2007. The certifying physician of each death was sent a questionnaire about medical end-of-life practices that had a possible or certain life-shortening effect.



**Results:** Of people who died following a medical end-of-life decision (N=1733), 4% had a living will requesting euthanasia. Of these people, 37% did not receive euthanasia. Of those who died of euthanasia, 42% did not have a living will requesting it. People whose underlying cause of death was cancer (OR=6.8; 95%CI [2.66-17.38]) or a neurological disease (OR=10.6; 95%CI [3.11-36.40]) were more likely to have a living will compared to people who died of other conditions. Having a living will requesting euthanasia was less likely for people of 65 year and older (OR=.4; 95%CI [.24-.76]), and for those dying in hospitals (OR=.3; 95%CI [.14-.49]) or nursing homes (OR=.3; 95%CI [.09-.86]) compared to those dying at home.

**Conclusion:** Having a living will requesting euthanasia was related to the patient's disease, age and place of death. The preferences regarding euthanasia documented in a living will did not correspond to end-of-life decisions in more than one third of cases. More research is needed into the reasons and circumstances in which a living will requesting euthanasia is not followed.

**Abstract number:** P1-285

**Abstract type:** Poster

## Advance Care Planning (ACP) - For Me or for you? An Expression of Egoism or Duty to Others?

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**Background:** Advance Care Planning is promulgated to promote patient's autonomy with respect to their physical wellbeing (for example Do Not Attempt Resuscitation orders) and protect against medical paternalism especially in the case of future loss of mental capacity. The concept of ACP as solely an egotistical approach to try to control physical death has been challenged (1). Autonomy enables a patient to be a moral agent and many feel reciprocal duty to their family.

**Aim:** To revisit the concept of ACP to consider whose interests (patient, family, doctors, or care establishments) are taken into account. Specifically does ACP purely support a liberal autonomy concept related to patients' personal physical wellbeing or wider concepts of autonomy such as duty to others?

**Methods:** A literature review was conducted using terms: Advance Care Planning, autonomy, duty, responsibility, patients, family, carers. UK Policy Documents were examined.

**Results:** Dominant theme in literature review is promotion of liberal autonomy but through a medical model focussing on treatment or rather not treatment of physical conditions in case of future loss of mental capacity. Most emphasis is on negative autonomy i.e. treatment refusals. Many patients do not want to be a burden. Notable exceptions show that patients use ACP to try to reduce the burden on relatives of decision making and/or preparation for death (1). UK policy documents focus on patient autonomy and physical wellbeing and clearer medical decision making.

**Conclusions:** Patients may reflect privately on how ACP decisions could impact on family. ACP in the UK focuses narrowly on patient autonomy and physical issues like DNAR. Widening the context to discuss impact of ACP decisions with family could promote the autonomy of the patient as a moral agent and enhance the benefits of ACP for patient 'me' and others 'you'

(1) Singer PA et al Reconceptualising Advance Care Planning From the Patient's Perspective Arch Intern Med 199;158 879- 88

**Abstract number:** P1-286

**Abstract type:** Poster

## What's in a Name? That which we Call Palliative Sedation - A Qualitative Study among Swedish Palliative Care Physicians and Nurses

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**Background:** Palliative sedation (PS) is an intervention aimed at relieving unbearable suffering at the end of life. There is scarce knowledge about this intervention in the Swedish palliative care context.

**Aim:** The aim of this study was to examine perspectives on palliative sedation among Swedish palliative care physicians and nurses.

**Methods:** Thirty-three in-depth interviews with palliative care physicians (n=10) and nurses (N=23) were conducted. The interviews were analysed with qualitative content analysis.

**Results:** Palliative sedation was, in general, regarded as an accepted intervention in palliative care at the end of life. Several different definitions of the concept were used by the informants: PS (i) as a treatment to relieve anxiety by intermittent lowering of the patient's consciousness, (ii) as an unintended side effect of medication for symptom control or (iii) as intended continuous sedation to relieve refractory severe symptoms. Intended continuous sedation seldom needed to be used according to the participants. The informants stressed that palliative sedation can only be justified ethically by the presence of distressing symptoms in need of alleviation, and that PS also needs to be accepted by the patient. Therefore, the decision-making of PS should be shared between the physician and the patient. PS can never be justified solely by the patient's autonomous wish, in case the physician finds no medical indication. Physical, and in a sense, psychological suffering were considered appropriate indications for PS, while social suffering was not, and there were different opinions concerning existential suffering.

**Conclusion:** There seems to be a need for distinct definitions of PS, as well as more explicit guidelines for this intervention for health care staff working with patients in need of advanced palliative care.

## Family and care givers

**Abstract number:** P1-287

**Abstract type:** Poster

## The Impact of the Carer Support Needs Assessment Tool (CSNAT) in Community Palliative Care Using a Stepped Wedge Cluster Trial

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**Background:** Family caregiving towards the end-of-life entails considerable emotional, social, financial and physical costs for carers. Evidence suggests that good support can improve carer psychological outcomes.

**Aim:** To investigate the extent to which the carer support needs assessment tool (CSNAT) used in end of life home care improves carers' carer strain and distress and mental and physical wellbeing.

**Methods:** A stepped wedge design was used to trial the CSNAT intervention in three bases of Silver Chain Hospice Care in Western Australia, 2012-14. The intervention consisted of at least two visits from nurses (2-3 weeks apart) to identify and review carers' needs. The outcome measures for the intervention and control groups were the carer strain and distress as measured by the Family Appraisal of Caregiving Questionnaire (FACQ-PC), the carer mental and physical wellbeing as measured by SF-12v2, and carer workload as measured by extent of assistance with activities of daily living, and at baseline and follow up.

**Results:** Total recruitment was 620. There was 45% attrition for both groups between baseline and follow-up mainly due to patient deaths resulting in 322 carers completing the study (233 in the intervention group and 89 in the control group). At follow-up, the intervention group showed significant reduction in Carer Strain relative to controls, p=0.018, d=0.348. Decrease in Carer Distress was also observed for the intervention group, while a greater increase in carer workload was observed for controls, although both results were not statistically significant after controlling for covariates.

**Conclusions:** The CSNAT implementation led to an improvement in carer outcomes. Effective implementation of an evidence-informed tool represents a necessary step towards helping palliative care providers better assess and address carer needs, ensuring adequate family carer support and reduction in carer strain and distress throughout the caring journey. (Funded by ARC)

**Abstract number:** P1-288

**Abstract type:** Poster

## Family Caregivers of Frail Elderly at the End of Life: Predicting Overburdening

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Current literature shows that health interventions and healthy life habits contribute to increase life expectancy while maintaining functional independency (Fries, 2000). However, certain pathologies are still more frequent among elderly. It is calculated that, in year 2020, approximately 6,2% of the Spanish population will be 80 or more years old (INE, 2011). The present study focuses in family main caregivers of frail elderly at the end of life. We follow the definition that Botella et al. (1998) make of frail elderly: a person that presents advanced age; some degree of disability; multiple chronic diseases; polypharmacy; geriatric symptoms; and high risk of hospitalisation, institutionalisation, acute disease or death. Recent research point out that a high proportion of family caregivers of elderly patients at the end of life feels overburdened (Soto et al, 2014).

The present study aims to analyse the elements that might relate to overburden in family main caregivers of frail elderly patients at the end of life, taking into account variables of the patient and the family caregiver.

It is a cross-sectional study, in which participated forty hospitalised frail elderly at the end of life, and their family main caregivers. Barthel Index, Hospital Anxiety and Depression Scale, and Zarit Burden Interview were used.

Linear regression's analyses were carried out. The model that best predicted the variance of overburden in the family caregivers included: depression's level of the family caregiver, depression's level and independency level of the frail elderly patient. This model explained 40,7 % of the observed variance.

Results from this study highlight the need (and the opportunity) of interventions that pursue the psychological wellbeing of family main caregivers and frail elderly patients at the end of life, preventing and reducing the caregiver's overburden.

Research funded by the Spanish Science and Innovation Department (PSI2010-19426).



**Abstract number:** P1-289  
**Abstract type:** Poster

## Are Family Meetings Feasible and Equitable in the Acute Setting? A Retrospective Audit

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**Background:** Evidence suggests that 'Family Meetings' (FM) with specialist palliative care teams (SPCT) are effective in meeting needs. Evidence-based guidelines highlight the uncertainty around optimal formats. In the acute hospital setting where length of stay is relatively short and decision making is rapid, FM implementation may be more challenging. In order to develop feasibility and modelling FM for further testing, we aimed to determine

- 1) proportion of dyads given FM
- 2) timing from referral to SPCT
- 3) who attends
- 4) purpose
- 5) whether patient characteristics are associated with whether FM is held.

**Methods:** Retrospective file review n=100 consecutive patients referred to SPCT from January 2014. Data extracted to purpose-built anonymised database. Descriptive analysis for Obj's 1-5, logistic regression for Obj 6. Family defined in line with NICE guidelines.

**Results:** Patient characteristics: 46% male, 61% white, 60% cancer, median age=70 (range 20-97).

- 1) 73% had a family meeting, of which 42% were impromptu and 58% planned.
- 2) FM conducted median 1 day after SPCT referral.
- 3) Attended by children (37%), spouse (18%), spouse+children (22%), siblings (7%). Attended by CNS only (32%), medic only (27%), social work only (12%), MDT (27%).
- 4) Purpose was poor prognosis (40%), treatment/withdrawal planning (29%), discharge planning (22%).
- 5) No associations were found for pt characteristics and whether FM was held, or for whether FM was impromptu or planned.

**Discussion:** The vast majority of referrals to SPCT are offered a FM (73%), and the majority of these are planned (58%). The median time to FM from referral is 1 day, although only a minority (27%) are multidisciplinary. It appears that FM is offered irrespective of patient characteristics. These data suggest feasibility of FM and equity of provision in an inner-city busy acute setting. This suggests that the intervention is appropriate for further testing with respect to outcomes.

**Abstract number:** P1-290  
**Abstract type:** Poster

## Informal Caregivers in Critical End of Life Situations

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**Background:** Terminally ill persons often voice a desire to die at home, spending their final days in familiar surroundings and being cared for by those closest to them. Informal caregivers who are committed to fulfil this wish face a number of burdens when caring for a person at the end of life.

**Aims:** The study aims at identifying burdens, challenges and critical situations from the point of view of informal caregivers, and it explores their coping strategies helping them to overcome the encountered difficulties.

**Method:** In two different regions of Switzerland 25 interviews with informal caregivers caring or having cared for a person at the end of life at home have been conducted. For analysis, a grounded-theory approach has been applied.

**Results:** The various stressors encountered by informal caregivers lead them to experience five different categories of straining emotions. It is less the stressors themselves, but more the emotions which influence how the caregiving situation is experienced. The different emotions are:

- (1) feeling tired and overburdened due to the strain of caring, the lack of sleep and the variety of tasks,
- (2) feeling alone and abandoned due to a lack of support and the difficulty to find someone to talk to,
- (3) experiencing grief and fear due to the confrontation with illness and death,
- (4) feeling helpless because of the lack of knowledge about the illness, possible symptoms and best-practices in caring for a person at the end of life, and last but not least,
- (5) feeling having lost control over their own life.

**Conclusion:** The study contributes to a better understanding of end of life situations when informal caregivers are providing care at home. The results will lead to the development of instruments and workshops that reinforce and support informal caregivers, helping them to overcome the difficulties and straining emotions associated with informal caregiving. The study has been funded by the Swiss National Science Foundation.

**Abstract number:** P1-291  
**Abstract type:** Poster

## Informal Caregivers at the End of Life: Modelling of a Complex Situation

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**Background:** How informal caregiving for a person at the end of life at home is experienced by the caregiver and the patient is determined by a number of different factors.

**Aims:** In the context of Swiss national research program, an integrated model has been elaborated with the aim of a better understanding of the diverse interactions and effects influencing caregiving situations at the end of life at home.

**Method:** The basis for the model are 25 narrative interviews with informal caregivers having cared for a person at the end of life at home. The interviews which have been conducted in German and in French in two different regions in Switzerland have been audiotaped, transcribed and analysed with a grounded-theory approach.

**Results:** The model shows how stressors and available resources originate at different levels of the system (micro-, meso-, and macro-system) and that therefore, not only the caregiver and the patient must be considered, but politics, institutions and professionals as well.

**Conclusion:** In order to ensure a satisfactory experience for all actors concerned, and to adequately support informal caregivers, it is important to get involved at all levels of the system. The study has been funded by the Swiss National Science Foundation as part of the national research program NRP 67 'end of life'.

**Abstract number:** P1-292  
**Abstract type:** Poster

## "Because we Are Girls, Everybody Had Much Higher Expectations." Gender Aspects of Informal Care at the End of Life

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**Background:** Informal care for people at the end of life is in many ways shaped by gender-specific concepts, ascriptions and norms.

**Aims:** As part of a recent study on experiences, needs, concerns, and resources of informal caregivers, it has been investigated how gender ascriptions influence the experiences of male and female informal caregivers providing care for a person at the end of life at home.

**Method:** In two different regions of Switzerland 25 narrative interviews with informal caregivers caring or having cared for a person at the end of life at home have been conducted. 20 participants were women, five were men. For analysis, a grounded-theory approach has been applied.

**Results:** On the one hand, given the still dominant traditional division of labour between men and women, only few men provide informal care at home. On the other hand, men who engage in providing care for relatives get more recognition and support than female caregivers - not least from health care professionals. While in the narratives of male informal caregivers the taking over of nursing tasks which are typically seen as feminine is an important subject, female informal caregivers emphasise rather the 'naturalness' of their activities, leading them to experience much more (internal and external) pressure than men do.

**Conclusion:** Informal care entails high burdens for - male and female - caregivers. Because these burdens are experienced differently according to gender, awareness for the powerful gender ascriptions which perpetuate themselves in norms and actions is essential for gender-sensitive policy and practice. Accordingly, supportive action by extension services has to consider the gender-specific differences when claiming professional assistance and provide a really 'universal coverage' for male and female caregivers. The study has been funded by the Swiss National Science Foundation as part of the national research program NRP 67 (grant-number 406740\_139243).

**Abstract number:** P1-293  
**Abstract type:** Poster

## Meaning in Caregiving for Parent Caregivers of Children with Life-limiting Illnesses

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**Background:** When children are born, parents expect to care for them. For some parents, however, a child's diagnosis of a life-limiting illness transforms them into caregivers in ways that parents of predominantly well children are not. Stress is inherent in this situation but positive aspects are less documented.

**Aims:** This research aimed to understand the factors that allow parent caregivers to grow in the face of the stressful circumstances of caring for a child with a life-limiting illness.

**Methods:** Data were collected by a cross-sectional survey that included measures of depression, burden, spirituality, posttraumatic growth, meaning in caregiving, optimism, and self-esteem. Participants (N=273) were recruited through affiliations with children's hospices and hospitals in Canada and the United States. Both mothers and fathers were encouraged to participate and more than one caregiver per family could enrol.

**Results:** While the stresses are numerous and life-changing, many parents also demonstrated growth as measured by the Post Traumatic Growth (PTG) Inventory (Tedeschi and Calhoun, 1996). Two structural equation models were tested to determine factors in the positive outcomes. The formative model - the direct impact of personal resources (meaning in caregiving, optimism, and self-esteem), spirituality, and burden on PTG - fit well but the impact on growth was inconclusive. The process model explored the impact of personal wellbeing (self-esteem, optimism, depression, and spirituality) on meaning in caregiving and indirectly on PTG; this model fit well and strong support for the hypotheses was generated.

**Conclusion/discussion:** This research demonstrates that particular attributes reflected in personal wellbeing are a precursor to the process of positive meaning making, which then in turn contributes to growth. The path to posttraumatic growth is complex; this research contributes to further elucidating it.

**Abstract number:** P1-294  
**Abstract type:** Poster

## Relatives' Matched with Staff's Experience of Patient's Dying in ICU

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**Background:** Intensive Care Units (ICU) exist to support patients through acute illness that threatens their life. Although ICUs aim to save life, they are also where a significant proportion of patients will die with international mortality rates ranging from 15-24%. There has been no previous research on deaths in ICU triangulating the experience of doctors, nurses and families through face to face interviews.

**Aim:** To explore the experience of relatives and staff of patients dying in ICU using qualitative grounded theory approach.

**Methods:** Consecutive patients were identified who were dying in ICU. Family members were met by the researcher prior to the patient's death. The ICU nurse and doctor most involved were interviewed within 48 hours of the death. The family were interviewed two weeks later. Interviewees described their experience of the patient's dying and death in ICU. Recruitment until data saturation and thematic analysis following grounded theory approach occurred concurrently.

**Results:** Ten triads recruited over 6 months (family, nurse and doctor) were interviewed in

relation to 10 patients.

In caring for the patient who is dying in ICU and their family, nurses practise deeply held values to their satisfaction with creativity and autonomy. Families appreciate kindness, attention and sensitive regular communication from nurses and doctors. Frequency of contact with doctors is not ideal. Limiting access according to ICU protocol is distressing for grieving relatives. Nurses determine access to pastoral care. Doctors articulate their struggles with decision making, determining prognosis, witnessing the grief of relatives. Some doctors wish to have a greater part in care of the dying patient.

**Conclusion:** Distress among nurses previously reported in ICU literature and attributed to disenfranchisement by the medical profession was not evident. In contrast doctors appear to struggle to express and practice what they value in caring for the patient who is dying.

**Abstract number:** P1-295

**Abstract type:** Poster

## Family Caregivers' Involvement in Caring for a Hospitalized Patient with Cancer and their Quality of Life in a Country with Strong Family Bonds

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**Background:** Being involved in caring for family members during illness is part of Indonesian culture, even during hospitalisation. It is unknown which factors influence the quality of life (QoL) of family members taking care of their loved ones.

**Aims of study:** To identify factors influencing the QoL of family caregivers of hospitalised patients with cancer in Indonesia.

**Methods:** A cross-sectional survey was performed. Data were collected in a general hospital in Yogyakarta from September to December 2011. Family caregivers of cancer patients were invited to participate. Regression analysis was used to determine which aspects of caring and which demographic characteristics influenced their QoL. The Caregiver Quality Of Life Index-Cancer questionnaire was used to measure the QoL.

**Results:** One hundred of 120 invited caregivers (83%) completed the questionnaire. Being involved in psychological issues in caring ( $\beta = 0.374$ ;  $p = 0.000$ ), younger age ( $\beta = -0.282$ ;  $p = 0.003$ ), no previous caring experience ( $\beta = -0.301$ ;  $p = 0.001$ ), and not being the spouse ( $\beta = -0.228$ ;  $p = 0.015$ ) negatively influenced the QoL and explained 31% of the variation ( $\text{adj}R^2 = 0.312$ ;  $F = 12.24$ ;  $p = 0.000$ ). Gender, education level, and time spent on caring did not influence the QoL of family caregivers.

**Conclusions:** Our findings identified modifiable factors such as dealing with psychological issues and lack of experience in caring which negatively influenced the QoL of family caregivers. These factors are potential targets for intervention strategies. Education and intervention programs focusing on dealing with psychological problems in cancer care might improve the QoL of both patients and their families.

**Keywords:** Cancer, family caregiver, hospitalisation, Indonesia, oncology, quality of life

**Abstract number:** P1-296

**Abstract type:** Poster

## Implementing a Complex Intervention to Support Family Carer-led Assessment and Support: Key Components of a Training and Support Toolkit

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**Background:** The Carer Support Needs Assessment Tool (CSNAT) intervention facilitates a carer-led process of assessment and support. It represents a change in practice from current practitioner-led approaches that requires targeted practitioner training and support.

**Aim:** To test and revise a CSNAT toolkit for palliative care for implementation of carer-led assessment and support in practice, informed by the Promoting Action on Research Implementation in Health Services (PARIHS) Framework.

**Method:** 36 palliative care services took part including specialist community teams, hospice at home and social work/family support teams. The research team delivered one day training on using the CSNAT for carer assessment and support: reflection on existing approaches; background to the CSNAT and interactive sessions on integrating the CSNAT in practice. 2-3 practitioner 'champions' per site attended (82 in total) then cascaded training and facilitated implementation within sites. Cross-service peer support was facilitated through twice monthly skype/webex discussion sessions. The PARIHS Framework informed analysis of champion qualitative interview and skype/webex field notes and revision of materials for wider sustainable roll out of the CSNAT.

**Results:** The finalised CSNAT toolkit addresses:

- (1) the nature of the evidence - underpinning policy and research, stages of the CSNAT approach and its benefits;
- (2) organisational context - recommended preconditions for internal managerial, administrative, and IT support
- (3) internal facilitation - resources for champions to cascade training, FAQs and practice-based examples from other services and
- (4) external facilitation by the research team through webex support networks and information exchange.

**Conclusion:** The toolkit addresses key components for successful implementation of the CSNAT to achieve evidence based, comprehensive carer-led assessment and support in practice.

**Funder:** Dimpleby Cancer Care Research Fund

**Abstract number:** P1-297

**Abstract type:** Poster

## A Critical Review of Carers' Perceptions of Palliative Patients' Symptom Distress

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As palliative care is being increasingly provided by family caregivers in the community, health care professionals depend on proxies to provide a precise and reliable assessment of the patient's general condition. It is thus vital to determine how reliable information by proxy is, since this affects patient care and symptom control.

The aims of this review are to analyse and explore reasons for the various perceptions of formal and informal carers of adult patients receiving palliative care.

A focused search of the literature was conducted using online databases, limited to journal articles publishing primary research studies, systematic reviews, meta-analysis and critical reviews. The pertinent data was then filtered in accordance to the set inclusion criteria and analysed using the PRISMA (Preferred Reporting Items of Systematic Reviews and Meta-Analyses) checklist.

The number of research articles eligible for the review was twenty-four, twenty-three of which were primary research studies and one systematic review. These were held across various countries and sections of the community, mostly during the patients' illness and among patients with various diseases most of which were advanced cancer or advanced metastatic cancer. In all of the studies, the proxy was never chosen by the patient.

There is no consensus about whether proxy and patients agree about their perception of distress. This is possibly dependent on symptom conspicuousness and visibility. General practitioners and district nurses differ greatly in ratings of difficulty of symptom control mainly due to their levels of confidence and training at treating certain symptoms. It is argued that family care givers are reliable at rating the level of symptom distress especially if the complaint is physical as opposed to psychosocial. However, it is contended that informal carers are not always in concordance with the patient and usually over-estimate symptom burden, and accuracy does not progress over time.

**Abstract number:** P1-298

**Abstract type:** Poster

## Little Things Mean a Lot: Improving the Support of the 'Families' of Patients Approaching the End of Life

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**Background:** 'One Chance to Get it Right', 2014, emphasised support for 'families' of those dying. Timely support reduces risk of abnormal grief reactions. An integrated care organisation in the north of England, (hospital and community), has an active End of Life Steering Group driving change.

**Aim:** To improve the experience of 'families' of all patients approaching the end of life.

**Methods:** Several initiatives including carers of patients approaching end of life on the district nursing caseload, and the development of a cross-boundary carers care plan ensures the needs of carers are not forgotten. In addition, genograms and a carer's care-plan has been included in our local 'Individual plan for care of patients thought likely to be dying'. The acute trust has created an 'oasis' room, which alongside 'comfort' packs, identified showering and catering facilities enables families to have much needed time away from the ward. Free parking and open visiting allow unhindered access for distressed families. Refurbishments to the hospital prayer room and growth of the chaplaincy team provide quiet space for reflection and a listening ear. The hospital mortuary has been refurbished. Communication skills training for mortuary staff, the use of 'last thoughts and wishes' cards, seeded memorial cards and assistance with hand-printing has led to the development of a compassionate and caring bereavement service.

**Results:** The use of carer's care plans has contributed to meeting the 36 standards set for End of Life care in the community. The Oasis room is documented as being used every day and hand-made comfort packs are appreciated by families. We have seen an increased use of the prayer room (and prayer requests left) and chaplaincy services. Feedback from families is collated by specialist palliative care who trouble-shoot in real time and feedback successes to teams.

**Conclusion:** A number of little changes have improved the support given to families at a difficult time.

**Abstract number:** P1-299

**Abstract type:** Poster

## When Is the Decision Made to Place a Family Member with Dementia in a Care Home?

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**Background:** This qualitative study is based on interviews with informal carers of people with advanced dementia. It is part of a UK-wide mixed methods programme to develop a complex intervention to improve the end-of-life care for patients with advanced dementia and their carers.

**Aims:** To identify determinants of informal carers' decision to place a family member in a residential care home.

**Methods:** Using a topic guide we interviewed 14 carers, 5 male, 9 female. Eleven were caring for mothers, one a father and two for their husbands. At the time of interviews all except one family member were already living in care homes. Interviews lasted approximately one hour, were audiotaped, transcribed verbatim and analysed for thematic content by two

researchers. We used a rigorous approach working to the quality framework recommended by Spencer et al (2003).

**Results:** Most of the informal carers had been caring for their relative for several years prior to care home admission. In this group, care home admission was mostly not pre-planned but a direct consequence of an unexpected and sometimes fast deterioration in their family member's health; in some cases as a result of being hospitalised. These deteriorations caused numerous problems including incontinence, inability to walk, wandering, getting lost and aggression. It was these changes which led to the carers being unable to continue to cope with their caring role.

**Conclusion:** Informal carers need better access to information about the nature and course of dementia. Many are unprepared for acute changes in their family member and make the decision for care home admission when they can no longer cope with the competing demands of the caring role e.g. maintaining their family member in their own homes, looking after their own family and working full time. This could help with future planning at an earlier stage and may help reduce the stresses involved placing a family member in a care home.

**Funding:** Marie Curie Cancer Care

**Abstract number:** P1-300

**Abstract type:** Poster

## Delivering and Participating in a Psycho-educational Intervention for Family Carers during Palliative Home Care: A Qualitative Study from the Perspectives of Health Professionals and Family Carers

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**Background:** Family carers in palliative care have a need for knowledge and practical support from health care professionals, resulting in the need for interventions.

**Aim:** To explore the perspectives of health care professionals and family carers of delivering and participating in a psycho-educational intervention in specialised palliative home care.

**Methods:** A psycho-educational intervention was designed for family carers based on a theoretical framework. The intervention was delivered over three sessions based on an intervention manual. An interpretive descriptive design was chosen. Data were collected through focus group discussions with health care professionals and individual interviews with family carers, and analysed using framework analysis.

**Results:** In the perspectives of both health care professionals and family carers, the delivering and participating in the intervention was described as a positive experience. Although the content was not always adjusted to the family carers' individual situation, it was perceived as valuable. Consistently, the intervention was regarded as something that could make family carers better prepared for caregiving. Health care professionals found that the work with the intervention demanded time and engagement and that the manual needed to be adjusted to suit each group's characteristics. The experience of delivering the intervention was something that gave satisfaction and contributed to insights into their work.

**Conclusions:** In the perspectives of health care professionals and family carers, the psycho-educational intervention had important benefits and there was congruence between the two groups in that it provided reward and support. In order for health care professionals to carry out psycho-educational interventions, they may be in need of support as well as securing appropriate time and resources in their everyday work.

**Abstract number:** P1-301

**Abstract type:** Poster

## "You Are 24 Hours under Pressure" - Interaction of physical and Social Burden with Psychological Effects in Informal Caregivers of Brain Tumor Patients

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**Background:** Informal caregivers (IC) of dying cancer patients are confronted with many burdening situations, e.g. care at home. It is unknown whether this burden is associated with the underlying disease, in particular in case of brain tumor. The aim of this study was to analyse whether the perceived physical, psychological and social burden of IC of patients with a brain tumor, experienced during the time of home care, is related to psychological effects at a later date in comparison to the IC of the non-brain tumor group.

**Methods:** A mixed methods approach was used. Quantitative analysis is presented here. IC were interviewed after the death of the patient (M=27.32, SD±7.75 months) and completed three questionnaires (PHQ-short, BSFC-short, SeiQoL). The sample was categorised according to the diagnosis of the patient and matched by age, time since death and relationship to the patient. Correlations were calculated using SPSS.

**Results:** IC of 17 patients with brain tumours (Glioblastoma Grade IV) and 11 patients with non-brain tumours were interviewed. IC were mostly female (75%) and on average 58.3 years old (SD±7.2). In our sample patients with brain tumors mostly died at home or in a hospice, while the patients of the other group died mostly at the hospital. We found a significant correlation between depressive symptoms, especially restlessness at the time of the interview and ex post rated perceived burden of home care, especially physical exhaustion (r=.492, p=.013), loss of strength (r=.459, p=.021), and impact on relationships (r=.648, p=.000). These correlations were influenced by the place of death of the patient and the prognosis of the diagnosis.

**Conclusions:** Since brain tumors, especially Glioblastoma Grade IV, have a very poor prognosis, IC of brain tumor patients felt more burdened in the interaction with others than IC of non-brain tumor patients. IC of Glioblastoma patients should thus be offered more support for the conservation of social resources.

**Abstract number:** P1-302

**Abstract type:** Poster

## The Troubled Water under the Bridge: Lack of Palliative Care Referrals for Heart Failure

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**Background:** End-of-life (EOL) services, such as hospice and palliative care, are often lacking even for the sickest heart failure (HF) patients. Use of these services is hampered by lack of availability and limited referrals due to the unpredictable disease course. Patients and caregivers often refuse services because of a misunderstanding of HF's terminality.

**Aims:** To determine whether caregivers of HF patients with a predicted survival of < 2 years understood disease terminality prior to and after the patient's death.

**Methods:** As part of a longitudinal study of 100 patient-caregiver dyads, caregivers were interviewed monthly until the patient's death and then post-death. Interviews immediately preceding and post-patient death were analysed to determine caregivers' perceptions of the terminality of HF.

**Results:** Of the 50 caregivers of patients who died, most did not understand the severity of the disease and 68% viewed the death as unexpected. When caregivers retrospectively reflected on the patient's illness, they recounted downward trends, but were not aware of its terminality. Caregivers who understood illness severity prior to death came to this realisation late in the disease trajectory. At the point of recognition, treatments were limited or withdrawn and the short-term use of EOL services was instituted.

**Conclusions:** The lack of perceived illness terminality has profound implications for patients and caregivers. Those who do not recognise the seriousness of the illness are less likely to accept EOL services. Clinicians also need to understand the HF EOL trajectory and that EOL discussions help patients and caregivers make informed choices; allowing them to receive quality care at EOL. Healthcare providers require education about the importance of discussions early in the disease trajectory so palliative care becomes a philosophy of care not merely a referral service for HF patients immediately preceding death.

**Funding:** U.S. National Institutes of Health

**Abstract number:** P1-303

**Abstract type:** Poster

## The Influence of Psychophysical Situation of Terminally Ill Patients on Distress of their Families

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**Background:** Families of terminally ill cancer patients are faced with significant demands that can seriously impact their physical and mental health. It is important for healthcare professionals to be aware of caregivers' support needs in order for these to be adequately addressed.

**Aims:** The purpose of the study was:

- to assess physical and psychological condition of patients with metastatic cancer
- to establish the influence of the patient's psychophysical condition on: the overall quality of life; the intensity of anxiety, depression and anger and the degree of distress in families of patients with advanced cancer.

**Methods:** The study involved 70 subjects, aged between 28 and 92 (37 women). The studied persons were classified into two groups: the first group (I) consisted of hospice patients with advanced cancer (n=35); the second group (II) involved the family members of cancer patients (n=35). We used:

- Questionnaire for patient, Hospital Anxiety and Depression Scale, Multidimensional Fatigue Inventory, EORTC QLQ-C15-PAL, Cantril Ladder (QoL), VAS1 (pain), VAS2 (fatigue);
- Questionnaire for family, Cantril Ladder (QoL), Hospital Anxiety and Depression Scale, Distress Thermometer, VAS3 (relationship).

The correlation level between variables was determined by the Pearson's coefficient. The influence of independent variables on the dependent variables were determined by means of variance analysis and multiple regression analysis.

**Results:** Analysis of the results showed that:

- the patients revealed high levels of pain and fatigue, poor quality of life;
- worse mental and physical condition of the patient was associated with higher level of distress of the family;
- there was a correlation between psychophysical condition of patient and level of anxiety and depression of his family.

**Conclusion:** The study shows that malignant disease associated with psychophysical symptoms significantly influences the distress and emotions of patients' family members.

**Abstract number:** P1-304

**Abstract type:** Poster

## Building Bridges within Families. Helping Parents Communicate with their Children about Illness and Death

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**Background:** Every year, 10% of all patients dying in this organisation have children. (2012: 10 parents, 25 children. 2013: 11 parents, 26 children). Research indicates that children often experience being overlooked and ignored during their parent's illness. Parents and their children often share how difficult it is to talk with each other about the illness, the children's fear of mom or dad dying, and that they need help to do this.

Not all children and teenagers know what palliative care means.

**Aims:** To prepare a small book, especially for children and young relatives, containing questions, explanations and answers relevant for this group about serious illness.

**Method:** In order to find the most relevant questions, a group of children who had ill parents was invited to the organisation. They toured the facilities and were encouraged to ask any



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question they considered important. These questions became the basis for the material in the book. An interest group, working specifically with caring for children and young relatives, used them to develop the explanations and answers presented in the book. Often, the book is handed out to the families before they arrive, so that their children may be better prepared for the visit.

**Results:** Adults tell us that the book offers them the opportunity to talk with the children about how they feel and what is going to happen with mom, dad, grandmother or grandfather. Many parents tell us that the book is helpful in their communication about the illness and approaching death.

**Conclusion:** Recently the third edition of the book was published.

The book is up-to-date with photos of staff members and surroundings, as well as updates to the text.

The book is never presented without an explanation or discussion with the family about how to use it.

Group: Four staff members in the organisation.

**Abstract number:** P1-305

**Abstract type:** Poster

### Sleep Disturbance and Related Factors among Family Caregiver of Advanced Cancer Patients

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**Objective:** Sleep disturbance of family caregivers (FCs) are common in the context of advanced cancer. The comprehensive factors for Sleep disturbance among the FCs of oncology patients have not yet been investigated in Taiwan. The purposes of this study were to investigate potential predictors of sleep disturbance for family caregiver of advanced cancer.

**Methods:** A descriptive, cross-sectional study was conducted among 172 FCs. Data were collected using the Pittsburgh Sleep Quality Index (PSQI) and wrist actigraphy. A linear regression model was set up as the main statistical method to identify the predictive factors for sleep quality among FCs.

**Results:** Seventy-six percent of the FCs of advanced cancer patients experienced some sleep disturbance. Higher fatigue, greater depression, more caregiving burden, and spending over 16 h on caregiving tasks each day were risk factors for sleep disturbances in female caregivers.

**Conclusions:** Sleep disturbance is common among Taiwanese FCs who have managed advanced cancer patients. FCs with risk factors for sleep disturbance should be identified and introduced to resources for assistance.

**Abstract number:** P1-306

**Abstract type:** Poster

### Administering of Palliative Care through Family Members under Rural Setting in India

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**Aim:** Our goal is to give a pain free good quality of life in these advanced stage cancer patients. Objective of this study is to identify the main difficulties in achieving the above goal in a rural village setting in India.

**Methods:** The initial plan is to create a nodal centre at District Head Quarter, Tamluk for the management of advanced cancer patients. Then we create different leaflets for each of the problems mentioned above in vernacular (Bengali). One on Constipation, one on Pain, one on Fever, one on Haematuria and so on with necessary advice on medications with their doses and procedure for administering them with the help of palliative care specialists and palliative care volunteers. All leaflets are to be given to the caretaking family members, who would be required to follow the written instructions.

**Results:** This allows the family members to give the needed care to the terminally ill cancer patients without presence of a medical professional or repeated visits to a medical centre saving their time and energy for giving care.

**Conclusions:** There is a wide gap of trained manpower in the field of palliative care in rural areas of West Bengal, India. Dedicated groups from rural areas and the family members of the terminally ill patients need encouragement, education and proper training for tackling difficulties at home itself. The leaflets can be a valuable input in that direction.

**Abstract number:** P1-307

**Abstract type:** Poster

### The Palliative Care Patient's Role in the Formal Family Meeting

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**Introduction:** Formal family meetings (FFMs) are frequently used as a means of communicating with patients and families in the palliative care setting. Previous studies examining participants' experiences of FFMs have focussed on family members. Little is known about the patient's role in the meeting. This study seeks to examine the palliative care patient's level of involvement in, and experience of, FFM's in an inpatient hospice.

**Methods:** Mixed methods are used, using a variant of the triangulation design (the convergence model). Data collected comprises quantitative (retrospective chart review, analysed using SPSS 22.0 descriptive statistics and Chi-squares) and qualitative (patient interviews after the FFM, analysed using thematic analysis).

**Results:** 82/227 (36%) admissions during the 6 month study period involved a FFM, with younger patients ( $\chi^2 = 10.296$ ,  $p = 0.035$ ) and patients who were subsequently discharged being more likely to have had a meeting than those who died in the hospice ( $\chi^2 = 8.304$ ,  $p = 0.004$ ). The patient was present at 34% of meetings, with patients closer to death less likely to attend ( $\chi^2 = 16.064$ ,  $p = 0.003$ ). Themes generated from interviews included patient's sense of control, concern for their family, anger at family's questions, anxiety about the meeting, perceived benefits and satisfaction with the meeting, and views on the timing and frequency of meetings.

**Conclusions:** Just over one third of admissions involved a FFM. Only 34% of meetings had the patient present despite patients' desire for a sense of control and to have their own and their family's information and support needs met. Further study is needed to understand patients' reasons for non-attendance and their level of participation when present. Given that patients closer to death are less likely to attend, early FFMs may provide an opportunity for patients to be actively involved in the process.

**Abstract number:** P1-308

**Abstract type:** Poster

### Family Satisfaction with the Zone Palliative Care Program (ZPCP) - What Can We Learn from Implementing FAMCARE and FAMCARE-2?

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**Background:** The multiple assessments used in the Zone Palliative Care Program (ZPCP) help improve clinical care, and are valuable in research and administrative reporting. In response to Accreditation Canada's recommendation, the ZPCP has adopted the FAMCARE/FAMCARE-2 as a measure of family caregiver satisfaction of palliative care services. Items range from 1 (very satisfied) to 5 (very dissatisfied).

**Aim:** The aim of this study was to evaluate family caregiver satisfaction in the ZPCP (three hospices and a tertiary palliative care unit) between November 2010 and March 2014.

**Method:** The FAMCARE or FAMCARE-2 was mailed to the identified closest relative of the patient approximately 2 to 8 weeks after the patient's death. During the study time period, there were 2,663 deaths across all 4 sites. The total number of forms returned was 565, resulting in an estimated response rate of 21%.

**Results:** Overall, the results were very positive. For the FAMCARE, all items were rated as satisfied (S) or very satisfied (VS) by over 75% of participants across all sites, with the exception of 4 items (Q5, Q7, Q14, Q17). For the FAMCARE-2, the frequencies of S and VS responses for all 17 items were higher than for the FAMCARE. All items were rated as S or VS by over 75% of participants. The average subscale scores (FAMCARE-2) were very similar, ranging from 1.4 (physical symptoms and comfort, family support, patient psychological care) to 1.5 (provision of information). There was greater variability for individual sites.

**Conclusion:** Despite the high level of patient symptom burden, and recognising that the FAMCARE/FAMCARE-2 tool may be capturing health care experiences prior to the patient being admitted to a palliative care service, the reported level of family satisfaction was gratifying. The FAMCARE-2 questions are generally more applicable than the FAMCARE. The results also point towards recommendations for standardising administration of the tool throughout the ZPCP.

**Abstract number:** P1-309

**Abstract type:** Poster

### The Impact of Guidelines and a Documentation Form on Formal Family Meeting Practice

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**Introduction:** Formal Family Meetings (FFMs) are a vital tool in effective communication with patients and families. Audits in 2 specialist palliative care units (SPCUs) revealed a number of practice deficits. A complete audit cycle is presented here, comparing data before and after the implementation of staff guidelines and a standard form for documentation of FFMs.

**Methods:** All FFMs that took place from 1<sup>st</sup> Jan to 31<sup>st</sup> March 2009 were audited against quality standards developed by a multi-disciplinary working group. A number of practice deficits were identified, particularly regarding pre-meeting planning and post-meeting follow-up. Guidelines and a standard form containing checklist reminders were developed and implemented. Re-audit took place on FFMs from 1<sup>st</sup> Oct to 31<sup>st</sup> Dec 2013 and compared with 2009 data using Fisher's exact test.

**Results:** FFM practice had improved across a number of domains between 2009 and 2013. Patients were more likely to be offered the option of attending the meeting (78% 2013, 56% 2009,  $p = 0.006$ ), as well as being consulted regarding which family members should attend (83% 2013, 57% 2009,  $p = 0.033$ ). Staff preparation also improved, with a decision being made and documented re which staff members to attend in all cases in 2013 ( $p = 0.008$ ). A staff discussion took place immediately before all meetings in 2013 compared with only 10% of meetings in 2009 ( $p = 0.0005$ ). Staff debriefing took place after 96% of meetings in 2013 compared with 15% in 2009 ( $p = 0.0005$ ).

**Conclusions:** There were significant improvements in FFM practices following the implementation of staff guidelines and standard documentation form, particularly regarding pre meeting planning, post meeting follow-up and patient involvement.

**Abstract number:** P1-310

**Abstract type:** Poster

### Acceptability of a Home-based Physical Activity Intervention for Family Caregivers of People with Advanced Cancer

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**Background:** Family caregivers (FCs) of people with advanced cancer experience a wide range of difficult emotions, extreme fatigue, and decreased health. Finding ways to help FCs cope is needed. Physical activity (PA) may be one such mechanism as the physical and psychological benefits of PA have been well documented. Also, PA programs can be individually tailored to address self-care needs. Using Pender's Health Promotion Model as a theoretical guide, an evidence-based PA intervention was developed.

**Aims:** To evaluate the content, structure and process of the PA intervention and refine it, as necessary, to be acceptable to FCs.

**Methods:** A formative evaluation was conducted. FCs (n=10) providing care at home for



individuals with stage 3 or 4 cancer received the PA intervention for 6 weeks. Qualitative feedback about the content, structure, and process of the PA intervention was collected during a baseline home visit, weekly telephone calls, and follow-up interview. Data were analysed using content analysis. This was an iterative process with modifications made, as necessary, until the intervention was optimal and acceptable to FCs.

**Results:** The PA intervention was deemed acceptable to FCs. Caregivers reported that the flexibility of a home-based, individualised, lifestyle PA program, made it feasible for adherence. A collaborative approach, setting goals, using a simple PA log for self-monitoring, and receiving weekly telephone calls for coaching and support were perceived as helpful strategies that provided motivation to adhere to the PA plan. No modifications to the PA intervention were necessary.

**Discussion:** Rigorous development of a novel, evidence-based intervention provides an empirical foundation from which to proceed to pilot testing and efficacy studies with the aim to keep FCs healthier, potentially enabling them to provide care at home for a longer period and preventing them from becoming patients themselves.

**Funding:** Canadian Institutes of Health Research

Abstract number: P1-311  
Abstract type: Poster

### Carers and Healthcare Professionals' Views on Caring for Dying Patients in their Own Homes in North Wales

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**Aims:**  
- To explore the experience of caring for someone who wished to die at home in North Wales.  
- To explore the contribution of the home environment to the overall quality of a good death.  
- To identify the support that influenced the quality of the experience of dying at home.

**Approach:** Increasing numbers of people wish to die at home and view this as an indicator of a good death. However, there is limited evidence of the quality of this experience and its impact on carers' lives. Many people, particularly the elderly and those living alone will not die at home. Clarity of outcomes that are positive for home environment may be able to be shared with other places of death.

**Methods:** A qualitative approach, consisting of interviews of dyads of bereaved carers and a nominated Health Care Professional. The study was underpinned by a phenomenological theoretical perspective with a total of 28 participants interviewed. The Framework method was used and codes were obtained deductively. Codes that were identified within this study consisted of 'home', 'communication', 'support', 'carer experience' and 'adaptive equipment'.

**Results:** Carer experience of supporting someone to die at home is a complex mixture of satisfaction, demands and distress. Normality, control and fulfillment of patient wishes are key features of the home environment. Achieving these areas results in carers' feeling satisfied that they have supported a good death. However, the home environment exacerbates the strain on family carers as their own needs are very different from carers. Health care Professionals appeared to be aware of the needs to support the differing needs between patients and family carers but find it challenging to address both.

**Lessons learned:** Support that was viewed positively was based on coordinated and consistent care, sensitive communication skills. Professionals' views differed from some carers and sharing of concerns could lead to improvements in care.

Abstract number: P1-312  
Abstract type: Poster

### Empowerment of Family Care Givers Living with People with Dementia

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**Background:** Dementia is acknowledged to be an incurable disease in the need of a broad understanding of palliative care. Most people with dementia are living with and cared for by their relatives. A training course based on validation® following Naomi Feil invited family care givers and their relatives with dementia to share experiences and improve their everyday living situation.

**Aims:** The aim of the presented study is to discuss empowering effects of the training course and aspects of early palliative care for family care givers living in the community.

**Methods:** Within a participatory approach a qualitative study and a literature research were conducted. Three expert interviews with the trainers, one focus group with care giving relatives and three narrative interviews with families living with a person with dementia were performed. Typical situations of the audio transcript taken during the training course were identified and analysed. Content analysis was organised individually and within the interdisciplinary research team.

**Results:** The training course based on validation® had empowering effects in different dimensions:  
1) practical and theoretical support  
2) exchange of experiences  
3) cultivating an attitude and communicative behavior  
4) trust in careful frame conditions  
5) grief and bereavement accompany the living with dementia from the very beginning of the disease.

**Conclusion:** Empowerment of family care givers can be observed after attending the training course based on validation®. Breaking the silence that often is associated with dementia and talking about difficult and challenging experiences strengthens coping strategies. This can be interpreted within the palliative care approach as an early and helpful intervention and support in painful situations in every day life. This study is funded by the research advisory board of the Alpen-Adria University of Klagenfurt, Vienna, Graz

## International developments

Abstract number: P1-313  
Abstract type: Poster

### Identifying Good Practice in Relation to Palliative Care for People with Intellectual Disabilities: Examples from 12 European Countries. Report from the EAPC Taskforce on Intellectual Disabilities

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**Background:** An estimated 5 to 15 million EU citizens have intellectual disabilities (ID). The EAPC approved a 2-year taskforce on palliative care for people with ID (2012-2014).

**Aims:** To improve palliative care for people with ID throughout Europe by (a) gathering and sharing examples of good practice, and (b) developing consensus norms for palliative care of people with intellectual disabilities. This presentation focuses on (a).

**Methods:** In order to gather a wide range of examples, 'Group of Experts' was identified through the networks of the 12 members of the Taskforce (itself representing 9 countries). The Group of Experts consisted of 35 professionals in 18 countries who had expertise in the field of palliative care, ID, or both. They were asked to provide written examples of palliative care provision for people with ID. Analysis of the examples focused on their congruence with the 13 categories of the consensus norms, simultaneously developed by the Taskforce.

**Results:** 85 Examples were received from 12 European countries. Among them, practice illustrations were found for most of the 13 norms. However, the following was noted:  
(1) respondents appeared unsure what constitutes 'good practice';  
(2) the availability and nature of services for people with ID and palliative care provision varied greatly between countries, affecting the possibility of providing good palliative care to people with ID; and  
(3) good practice was often due to the passion of dedicated staff, rather than to supportive social and health care systems and structures.

**Conclusion:** It was beyond the scope of this project to assess the effect of national/regional differences in service provision on the availability and quality of palliative care for people with ID. This needs further study. More work is also needed to educate and support staff in what constitutes good practice. The new EAPC White Paper, providing European consensus norms for palliative care and ID, is an important first step.

Abstract number: P1-314  
Abstract type: Poster

### A Systematic Mapping Review of the International Palliative Care Research Literature

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**Background:** Globally, the need for palliative care services continues to outstrip supply. In order to attract greater global attention from policymakers, it has been argued that an international approach to research and advocacy is required. However, the extent to which an international approach to research is being taken is unknown.

**Aim:** This systematic mapping review presents a thematic analysis of all published international palliative care research. International research is characterised as studies focusing upon 2 or more countries, or global level organisations.

**Methods:** Five bibliographic databases (CINAHL, Cochrane Library, ASSIA, Web of Knowledge, Psychinfo) were searched for journal articles relevant to international and global palliative care/palliative medicine and end of life care. Inclusion/exclusion criteria were applied and data were extracted using a piloted extraction form.

**Results:** 311 relevant studies were included in the review. The first international palliative care research article appeared in 1985 and relevant literature has been published in 119 different academic journals. Research emanates from and focusses upon all world regions as well as an emerging body of work at global level. In total, 170 studies collected primary data and 141 were secondary analyses of existing data. Thematically, the most researched areas were: policy (n=87), evaluation (n=74) and stakeholder groups (n=49). The review revealed a predominantly observational research approach and few interventional studies were identified.

**Conclusion:** International palliative care research is a relatively new, but growing field. However, many gaps in the evidence base remain in terms of thematic focus and the quality of evidence being produced. The relative absence of interventional research demonstrating the effectiveness and cost-effectiveness of palliative care risks limiting the tools with which advocates can engage with international policymakers on this topic.

**Abstract number:** P1-315

**Abstract type:** Poster

## Development of Palliative Care Services in the Republic of Serbia

Downing J.<sup>1,2</sup>, Haraldsdottir E.<sup>1,3</sup>, Milicevic N.<sup>1,4</sup>, Lukic N.<sup>1</sup>, Baskott J.<sup>1,5</sup>, Rayment C.<sup>1,5</sup>

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**Background:** In 2009, the Ministry of Health in Serbia published a national strategy for palliative care, which acknowledged the need for palliative care services to be integrated into the government health system and provided throughout Serbia. An EU funded project supported the Ministry of Health to operationalise the strategy within the current health care system, between March 2011-November 2014.

**Aim:** To assist the Serbian Ministry of Health in the implementation of a strategy that will ensure high quality and sustainable palliative care services across the country.

**Method:** A team of national and international palliative care experts worked together in Developing and implementing a comprehensive model of palliative care service delivery. Developing and implementing a comprehensive education strategy for health and social care professionals including continuing education and academic programmes. Reviewing existing legislation that has an influence on quality of palliative care and providing recommendations for its improvement

### Results:

A model of palliative care service delivery developed along with supporting resources e.g. indicators and standards.

Currently there are 15 palliative care sites, across Serbia e.g. PC Units, with others under development.

More than 1,200 health care professionals have undergone continuing education and palliative care has been incorporated into the academic curriculum for medical, nursing and social work students.

Changes have been made to legislation in relation to the essential medicines list and the law on health care provision.

Four publications have been printed in Serbian on palliative care e.g. best practice guidelines

**Conclusion:** Over the life-time of the project palliative care service delivery in Serbia has been strengthened considerably. Future development needs to be based around sustaining current services and ensuring further development of services at all levels of care in Serbia.

**Abstract number:** P1-316

**Abstract type:** Poster

## Appraisal of the Impact on Palliative Care Development of the EU Funded Project 'Development of Palliative Care Services in the Republic of Serbia'

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**Background:** The EU-funded project 'Development of Palliative Care Services in the Republic of Serbia' was implemented between March 2011 and November 2014. The project aimed to support the Ministry of Health (MoH) to develop a comprehensive and modern system of palliative care in Serbia, accessible to all who require such care.

**Aim:** To capture the short term impact of the project through drawing on the experience of a range of project stakeholders including the MoH, partner organisations, training participants and those involved in developing palliative care policy and practice.

**Method:** Focus group discussions and semi-structured interviews were undertaken in September 2014. FGDs and interviews were set up by the project team. 8 participants were interviewed and 25 attended 4 FGDs. One palliative care unit outside of Belgrade was also visited and interviews held with 3 staff from the unit. All FGDs were undertaken through a translator along with 3 of the interviews. Interviews and FGDs were recorded, transcribed, checked and analysed using thematic analysis.

**Results:** One participant noted that 'This [the project] is a huge achievement, this is a game changer in this country. This project is the absolute fantastic example of how you can make a real impact'. Themes identified from the data included: the status of PC in Serbia prior to the project; the impact of education and training programmes; changing culture and communicating about dying; influencing colleagues; development of palliative care units; resistance to change; drug availability; co-ordination of services; bottom up/ top down change; policies, guidelines and academia. Challenges for the future were identified and the importance of sustaining momentum.

**Conclusion:** This project has been a 'top down/ bottom up' public health change initiative that has a real chance of bringing about lasting impact in palliative care development across Serbia and the potential to influence developments in the wider region.

## Medical sociology

**Abstract number:** P1-317

**Abstract type:** Poster

## How Do Professionals in Specialised Palliative Care Respond to a Wish to Hasten Death?

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**Objective:** Health professionals in specialised palliative care (HP-SPC) are often confronted with wishes to hasten death (WTHD). Studies show that for this situation oncology nurses or general practitioners are often inadequately prepared. While it is often discussed that WTHD may be altered by effective palliative care (PC), it is unknown how HP-SPC respond when they encounter WTHD. This study aimed to identify HP-SPC responses to WTHD in daily practice and their corresponding functions.

**Methods:** At four University hospitals in Germany HP-SPC with at least one year's experience in PC were selected. Narrative interviews were conducted with 19 HP-SPC. Transcripts were analysed using the documentary method. Subsequently, an inventory of responses to WTHDs was compiled, and their corresponding functions in the interactional context between patient and HP-SPC were reconstructed.

**Results:** On the patient level the responses categorised as symptom control, exploring the reasons and generating perspective, reorientation, and hope to ease patients' burden were of particular significance. On the interaction level, creating and maintaining a relationship was of key relevance. Various methods served the functions self-protection and showing professional expertise on the professional level.

**Conclusions:** Both personal and professional development is necessary in order to respond to the inherent challenges presented by WTHD. HP-SPC should enhance their skills in establishing and maintaining trusting relationships as well as their awareness about their own resilience. Future guidelines should be amended by these issues and integrated into palliative care training programs. Encouraging professionals' cooperation within and beyond the palliative care team can contribute to successfully delivering much needed support for patients with WTHDs.

**Abstract number:** P1-318

**Abstract type:** Poster

## From "Sociological Study of *Tobyo-ki*" to "Clinical Application of Caring through Writing"

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**Background:** What can sociology contribute to clinical medicine? Sociologists are generally not considered suitable specialists and therefore not considered essential in hospitals. In Japan, there is a social phenomenon of publishing true stories about the experiences of patients. This is called *Tobyo-ki*, and since the latter half of the 1990s, the number of such publications has remarkably increased along with the importance of patients' feelings. Most such books are written by cancer patients. The first author, a sociologist examined them from various viewpoints. *Tobyo-ki* has seldom been regarded as a worthwhile study subject in any field. However, focusing on the independent experience of living with cancer from the viewpoint of patients is very important.

**Aims:** The study aimed to clarify the significance of writing *Tobyo-ki* for authors by using a sociological approach to create a practical and effective program useful in clinical medicine.

**Methods:** The approach involved a qualitative study that surveyed 550 books of cancer *Tobyo-ki*, published between 1964 and 2009, and the approach comprised several interviews with the book authors. Analysis was based on narrative approach.

**Results:** The action of writing was found to create oneself anew, considering oneself, changing one's own interpretation, accepting the situation, and finding the meaning of oneself. Moreover, a specific quality, 'passive-activeness', was suggested to be revealed in writing *Tobyo-ki*.

**Conclusion:** Now that the significance of *Tobyo-ki* writing has been demonstrated, the authors have prepared for the clinical application of caring for patients with breast cancer through writing. Our interdisciplinary research developed from the sociological study received a Grant-in-Aid for Scientific Research, and ethical judgments have been completed. We are now starting the six 90-minute sessions. We plan to discuss the outcome of these sessions in our presentation scheduled for May 2015.

**Abstract number:** P1-319

**Abstract type:** Poster

## Do Health Carers Know where their Patients Wish to Die?

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**Aims:** Checking if a wish of place of death (PD) is known by professionals; if yes, is it respected; if no, why not.

**Background:** PC mobile team witnessed a lot of last days emergency hospitalisations and wondered if it occurred because no one asked the patient where they wanted to pass away. **Design:** Retrospective quantitative study by questionnaire sent to health professionals (HP). Incl: all adults living in a 167442 inhabitants area, deceased during the 1st semester of 2013 from natural cause. **Results:** 475 died, 241 have exploitable data. Women: 52.2%, mean 82y old. PD: home 11.2%, nursing homes 28.6%, hospitals 58.9%. 42% lived alone at home, 4% were completely isolated. 64.3% HP (acute care facilities, home care, nursing homes) did not know where their patient wanted to die. For 46.1% at least 2 persons could have known. Spontaneous reasons identified for not knowing where a person wished to die, were mainly the difficulty of talking about end of life and impaired communication. For those whose wish was known (n=86/241), family 41.5%, general practitioner 22.8%, hospital 13.2%, home care 13.8% had the information. Patients had transmitted their wish orally 76.7%, via written advanced directives 19.7%, mainly when disease worsened 39.5%. 66.2% died where they wanted. Among the others, they mainly died in hospital because family carers were exhausted and/or symptoms management was impossible at home. **Conclusion:** Patient wish of his own PD is insufficiently known. Not enough HP are interested in asking where their patients would prefer to die because of difficulties of dealing with the subject. In consequence, too many people died in hospitals whereas political determination wants to promote free choice as far as PD is concerned. Level of awareness should be raised among professionals dealing with patient with life-threatening prognosis. Support for spouses should be a priority. **Funding:** Réseau Santé La CôteVD Switzerland.

**Abstract number:** P1-320  
**Abstract type:** Poster

### Treatment Seeking Pathways for Romanian Cancer Patients - A Qualitative Study with Cancer Hospice Patients and their Relatives

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**Background:** In Romania cancer is the second cause for death with a mortality rate of 179.7 deaths in 100000 inhabitants. It has been recognised that due to proliferation technologic advances, medical specialisation, increased scientific knowledge base, that there is a need for someone from within the health care system to deliver guidance to patients in access to care.

**Aim:** To identify the cancer patients' institutional trajectory and the barriers in seeking effective diagnosis and treatment modalities in the Romanian health system.

**Method** Qualitative study, data were collecting using in-depth interviews, observation and field notes, photo voice. Purposive sampling with participants, from rural and urban area, both genders, and a large age group. Study population was represented by palliative care patients with good performance status (ECOG up to 3), no cognitive problems and by their appointed family member. Parallel coding done by 2 researchers (sociologist), results reviewed by clinical researcher. Ethics approval was given by local board.

**Results:** 46 subjects were enrolled in the study: 25 patients (17 from urban area, 20 women, age from 20-84) and 21 carers. There was not a standardised trajectory for the patients, GPs played a marginal role in the trajectory, public oncology hospitals and outpatients clinic in district hospital were usually just a temporary station till patients moved to a regional cancer centre or a private hospital. Family had the role of patient navigator Challenges were represented by overcrowded hospitals with overworked and less compassionate health care staff, lack of information on the disease, available treatments and planning of care, communication that does not foster hope, cost of medication, treatment, investigations, informal payments, travel to big cancer centres, bureaucratic system, complicated paper work to access some care packages, long ques. Financial aspects were a major theme for family members and rural patients.

## Health services research

**Abstract number:** P1-321  
**Abstract type:** Poster

### Transition from Children's to Adult Services for Young People with Life-limiting Conditions: Findings from Realist Evaluation Research in Belfast and Dublin

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**Background:** Improvements in care and treatment have led to more young people with life-limiting conditions living beyond childhood, which means they must make the transition to adult services. The loss of long-standing relationships with children's services combines with poor co-ordination of services to make this a daunting prospect for young people and their families. Moreover, there is little evidence on transition services in palliative care, with few models of good practice.

**Aims:** To describe service provision for the transition to adult services for young people with life-limiting conditions in Belfast and Dublin, and to identify organisational factors that promote or inhibit effective transition.

**Methods:** A realist evaluation using mixed methods. A questionnaire survey was forwarded to 60 health, social, educational and charitable organisations to identify current transition practices. Semi-structured interviews with young people with life-limiting conditions are currently being conducted. Focus groups with carers will be undertaken in November 2014.

**Results:** There was a 50% organisational response rate from the survey questionnaire. Findings highlight five context mechanism outcome (CMO) configurations that appear to facilitate the transition process: early commencement, a transition plan, development of self-

management skills in the young person, collaborative interagency and interdisciplinary working, and the presence of a key worker. Interviews with young people and focus groups with carers will allow refinement of CMO configurations.

**Conclusions:** We identify key facilitators that can contribute to the transition process from the perspectives of organisations, young people and parents/carers. These insights could help to minimise gaps in the continuity of care and associated morbidity for young people transferring to adult services.

**Source of funding:** The All Ireland Institute of Hospice and Palliative Care and HSC R&D Division, Public Health Agency.

**Abstract number:** P1-322  
**Abstract withdrawn**

**Abstract number:** P1-323  
**Abstract type:** Poster

### Palliative Doc Mobile - Access to an Electronic Palliative Care Patient Record Choosing the 'Right' Data - Results from a Focus Group

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**Aim:** PaDoMo aims to provide access to an electronic patient record using a defined data set in a palliative care network in Germany. By means of a mock-up data set a group of palliative care experts should judge completeness of data, intelligibility of data array, and data set's value for field of work.

**Method:** 6 experts from different sectors of palliative care provision were identified and invited. Each expert received a cover letter, a paper copy of a mock-up data set based on the German 'Informations system Palliative Care (ISPC)' which resulted from a previous project and additional information on the project. Participants were encouraged in terms of open reasoning to write up any comments on the mock-up data set. On a second assessment date each expert received access to an online survey. The questionnaire was compiled with SurveyMonkey® consisting of 5 questions on completeness, intelligibility of data array and everyday practicality on a five level scale (*strongly agree, agree, agree somehow, disagree, strongly disagree*). Additionally, for each question a field for comments was generated. Demographic data of each participant were raised.

**Results:** Of 6 participants invited to the study n=4 participants did respond. Mean of age was 49.5 years (range 47-51 years). All of them were females. Professions were nurse manager, hospice nurse, physician and social worker. Data set was rate as good (weighted average 2.6). All data fields were valuated as relevant for everyday practicality in palliative care provision.

**Conclusion:** The ISPC data set complies with requirements of palliative care provision. Comparing the responses reveals that completeness and mapping of palliative care patients (Question 1-3) get slightly better rating than the reference to own work question (4-5). This may be grounded in nurses or social worker missing professional group-specific data. This study is funded by Förderprogramm IuK and Gender Med. NRW

**Abstract number:** P1-324  
**Abstract type:** Poster

### Monitoring and Nursing Care for Patients Receiving Palliative Sedation at Home

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**Background:** In the Netherlands, nurses have a prominent role in monitoring and care for patients receiving palliative sedation at home. However, little is known about the nature of monitoring by nurses and differences between the ideal and actual care for these patients.

**Aims:** To explore ideal and actual aspects of monitoring and nursing care for patients receiving palliative sedation at home.

**Methods:** Qualitative study using 2 focus group interviews with 12 nurse specialists working in palliative care and individual interviews with 7 community care nurses. Nurse specialists were asked how monitoring and care ideally should be performed. Community nurses were asked how they actually perform monitoring and care in daily practice. The interviews were fully transcribed and analysed using the interview topics.

**Results:** We identified five themes: comfort; monitoring; patient care; family support; cooperation with general practitioners (GP). The nurse specialists found it difficult to define comfort; they indicated comfort as 'a state of peace, relaxation and relieving suffering'. They stressed the importance of monitoring and observation, using observation scales as indicated in the Dutch guideline Palliative Sedation. In contrast to this, almost all community nurses work on instinct and experience, hardly using standard observation scales. The nurse specialists as well as the community nurses all agreed that care and support for patients and their family should match the needs of these persons. However, nurse specialists emphasise the importance of a systematic approach. The majority of all nurses experience difficulties in communication and cooperation with GPs.

**Conclusions:** Nurses' involvement in monitoring and care for patients receiving palliative sedation is important and essential. However, nurses should act on a more systematic bases. Ongoing education, focused on using standards, observation scales and on cooperation with GPs, remains of utmost importance.



**Abstract number:** P1-325

**Abstract type:** Poster

## Getting Research Active! Where Are We Now & Where Do We Want to Be? Developing Research Infra-structure within Specialist Palliative Care Units (SPCUs) in a Strategic Palliative Care Network (PCN) in England

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**Aims:** Research within SPCUs has not received the same focus as other core elements of the modern hospice movement - pain and symptom control, compassionate care and teaching. 'Research in palliative care: can hospices afford not to be involved?' highlights research is required to ensure evidence-based care is provided, create a culture of enquiry, and provide evidence of cost-effectiveness. Within a regional strategic PCN in England, the aims were to: Describe the current position regarding SPCU's research activity Develop understanding about:

factors which facilitate and hinder research participation for individual SPCUs research aspirations of individual SPCUs and collectively as a region

**Methods:** A 10-item 'Survey Monkey' questionnaire, themed from the 'Research in Palliative Care' report, was disseminated in April 2014 to all Consultants, Associate Specialists, Chief Executives, and specific Senior Managerial Staff working within regional SPCUs (n=40). Two reminders were sent.

**Results:** Thirty-two participants responded (response rate of 80.0%). Four participants only completed the demographic information - leaving 28/40 (70.0%) respondents. All respondents reported they were active in collecting routine data for audit purposes with just under half (46.4%) currently undertaking ethically-approved research studies. All localities either had a research policy in place or were in the process of developing one for their local SPCU. All respondents showed an enthusiasm towards the principles of conducting ethically-approved research studies. The main issues hindering engagement were - limited funding, time and capacity; lack of infra-structure; and limited understanding about research governance.

**Conclusions:** To facilitate a more research-active environment, we are now aiming to develop a more collaborative regional SPCU infra-structure, promote greater awareness of current research activity, and provide further information about research governance.

**Abstract number:** P1-326

**Abstract type:** Poster

## Cancer Patients' Need for Palliative Care Estimated on Inpatient Services Use in the Last Year of Life

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**The aim** of the study was to investigate the scope and place of inpatient medical care provision for cancer patients in the last year of life to determine the need for PMC based on the actual use of inpatient health services in the region.

**Materials and methods:** We analysed the medical histories of cancer patients who were admitted to hospitals of all levels due to the deterioration of their illness and in need for palliative care in the last year of life.

**Results:** Patients who died from cancer in the last year of life received inpatient care at different levels (69.5 admissions per 100 patients per year). The admissions were made mainly to the municipal medical organisations (79.77±3.0% of all hospital admissions) and 20.23±3.0% to the regional specialised cancer hospital.

**Conclusion:** 220 beds used for providing medical care to cancer patients in the last year of life can be considered as the minimal need for PMC beds including those based in a specialist cancer hospital (33.36 beds) facing the current levels of cancer morbidity and mortality in the region as well as the effectiveness of the primarily outpatient care. The number of PMC beds used by cancer patients in the last year of life was 80.12% of the total number of beds for PMC provision calculated according to the standard recommended by the State Program on Health Development in the Russian Federation until 2020. So we have to keep in mind that up to 80% of the total number of PMC beds established should be allocated for cancer patients and only 20% left for specialist PMC provision for patients with other progressive diseases. This emphasises the importance of developing and using the criteria for identifying patients with chronic progressive non-cancer diseases who really need specialist PMC.

**Abstract number:** P1-327

**Abstract type:** Poster

## Living at Home with Advanced Cancer: What People Do and How they Manage their Activities of Daily Living in the Home Environment

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**Background:** Globally the number of people living with advanced cancer for extended periods of time is growing. Evidence shows that these people spend a significant part of their time in the home environment and up to 30% have problems with daily activities. Yet, little is known about what they do during the day and how they manage their everyday activities in the home environment.

**Aim:** To describe the everyday life of people with advanced cancer in the home environment including the specific activities that occupy their time and their perceived ability to manage and perform daily activities.

**Methods:** Based on a cross-sectional design a consecutive sample of 164 participants with different cancer diagnosis in advanced stages and a WHO functional performance score of 1-3 were included in the study. Participant reported their daily activities in structured self-completed time-geographic diaries and were interviewed by trained occupational

therapists using the ADL-Interview (ADL-I) combined with open-ended qualitative interview questions. Analysis of the data from diaries was conducted by use of descriptive Time Geographical analysis program, Rasch measurement methods were applied to generate linear ADL-I ability measures, and the qualitative data were thematically analysed.

The results indicate that daily life of people with advanced cancer is dominated by activities in the home environment. They report most problems with physically demanding household activities and express frustrations in not being able to maintain prior activities.

**Conclusion:** The study contributes significant knowledge on the specific daily activity problems and challenges people with advanced cancer experience in regard to managing at home. Researchers and clinicians can draw on this knowledge as a prerequisite for developing and implementing home-based goal-directed interventions.

**Abstract number:** P1-328

**Abstract type:** Poster

## Early Integration of General Palliative Cancer Care in Hospitals - An Organisational Intervention on a Surgical Ward

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**Aim:** Staff-related and organizational barriers need to be overcome in order to develop palliative care and its supporting infrastructure in daily clinical practice. We aimed to test and describe the use of a nurse-staffed phone line, with a focus on early identification and alleviation of patients' physical and psychosocial problems at home, patients' sense of security during their illness trajectory and advance care planning.

**Methods:** The intervention is targeted to patients with advanced gastrointestinal cancer and their relatives, who are offered at diagnosis telephone contact with a nurse with a specialism experience and expertise in the field of palliative care - the contact is lifelong. The phone line is open daily from 08:00-15:00. A proactive holistic approach is taken, including individual needs assessment, guidance, regulation of medication and follow-up in consultation with the patient's personal doctor. The nurse also acts as a sparring partner for colleagues and facilitates complex situations and processes. Contacts are described qualitatively in a log that is evaluated using descriptive statistics.

**Results:** Over 9 months 131 patients and 427 consultations were registered. Outgoing telephone calls to patients and caregivers (32%) and professionals (8%). Incoming phone calls (31%), and in-person meetings with patients and families during hospitalization or outpatient visits (29%). Of the percentage incoming calls, 10% were from patients, 7% from relatives, 11% from professionals (colleagues, specialist palliative care, oncology ward) and 3% from municipal care units.

**Conclusion:** The telephone service, staffed by one qualified nurse, is an interface that supports continuity and cooperation and could underpin more effective palliative care. The model provides options that support patients' and caregivers' quality of life by optimising symptom management at home and in hospital and by allowing for appropriate courses of action without inadvertent disruption.

**Abstract number:** P1-329

**Abstract type:** Poster

## Anticipatory Care Planning: "What is the ACP Package?" Challenges regarding Understanding, Purpose and Definition

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Advance Care Planning (ACP) is deemed increasingly important in terms of improving care for people nearing the End of Life (EOL). A 2 stage study (based on MRC phase 1 development of a complex intervention) was conducted in the care home setting in one UK region to:

1. Map, refine and implement a process for ACP.
2. Evaluate the process with residents, relatives/friends and Health and Social Care Staff (HSCS).

Stage 1 findings: Mapping showed ACP to be complex and varied. An 'expert group' agreed a new process for 'Anticipatory Care Planning' (AnCP) for those with and without mental capacity (see EJPC 21(4);193-5).

**Aim:** Phenomenological study of residents, relatives/friends and HSCS engaged in AnCP to explore their understanding.

**Method:** Interpretive phenomenological research in 5 care homes; in-depth semi-structured interviews conducted around individual resident cases, involving:

- Initial interview after first AnCP discussion.

- Follow up interview(s) - 3 monthly intervals.

**Results:** 9 resident cases (all residents lacked mental capacity): 21 participants (15 relatives; 6 HSCS); 28 interviews completed. Language use: terminology, abbreviations and definitions used resulted in varied understanding across HSCS and caused anxiety for some relatives. Being well prepared for engaging in AnCP discussions resulted in better experiences. Understanding the purpose of the meeting (eg level of decision making) and the 'role' of all participants in the discussions was sometimes lacking or confused.

**Conclusion:** For residents to be involved in AnCP, earlier initiation of discussions is required. The AnCP process was valued by relatives and HSCS, however preparation, information, lack of jargon, abbreviations, and having clarity of role and purpose are important to ensure positive experiences and outcomes for residents and their families. The role of education and training to facilitate the AnCP process and ensure clear and open communication is paramount to its success.



Abstract number: P1-330

Abstract type: Poster

## Health Care Utilization for Patients with Dementia near the End of Life: A Nationwide Study in Asia

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**Background:** End of life care in dementia has been studied increasingly, however, little was known in Asian population.

**Methods:** A nationwide, claim-based National Health Insurance Research Database in Taiwan was employed for study. We enrolled patients with dementia (Dementia<sup>ICD</sup>) and patients with cancer (Cancer<sup>ICD</sup>) who aged 18 years and above and deceased during 2007-2011, and surveyed their health care utilisation in the last one year of life. Cases deceased during 2009-2011 were checked for their use of hospice additionally because the palliative care program in Taiwan had just covered patients with dementia since 2009.

**Results:** 688 Dementia<sup>ICD</sup> and 7,808 Cancer<sup>ICD</sup> were enrolled. Dementia<sup>ICD</sup> were significantly older and had more comorbidities than Cancer<sup>ICD</sup>. In the last one year of life, there was no difference of the frequency of ED visit per patient between two groups. Median days of hospital stay of Dementia<sup>ICD</sup> was longer than that of Cancer<sup>ICD</sup> (46 vs. 37). The majority of specialty who was in charge of hospitalised care for Dementia<sup>ICD</sup> was internal medicine physicians (45.20%). The top three causes of hospital admissions and ED visits among Dementia<sup>ICD</sup> were pneumonia including aspiration related (13.8%), acute respiratory failure (11.6%), and sepsis (5.1%). The percentage of patients who received aggressive interventions among Dementia<sup>ICD</sup> and Cancer<sup>ICD</sup> were as following: nasogastric tube insertion (74.7% vs. 51.9%), endotracheal tube insertion (55.2% vs. 22.6%), tracheostomy (8.6% vs. 3.5%), invasive mechanical ventilation (58.6% vs. 26.9%), hemodialysis (17.6% vs. 5.5%), defibrillation shock (7.7% vs. 2.3%), cardiopulmonary resuscitation (31.3% vs. 9.8%). Among 443 Dementia<sup>ICD</sup> and 4,872 Cancer<sup>ICD</sup> who deceased during 2009-2011, only one Dementia<sup>ICD</sup> and 893 Cancer<sup>ICD</sup> received hospice care.

**Conclusions:** Comfort-oriented concept and skill of end-of-life care for patients with dementia should be strongly introduced to general population and medical professionals.

Abstract number: P1-331

Abstract type: Poster

## Consultation Practices of Dutch General Practitioners Caring for Palliative Patients: A Cross-sectional Study

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**Background:** Palliative care is considered an intrinsic part of primary care, however general practitioners (GPs) regularly face complex problems, for which expert consultation is needed. Consultation practices of GPs, taking into account the full range of available consultation facilities, are largely unknown.

**Aims:** to investigate the extent and characteristics of palliative care consultations, as requested by GPs.

**Methods:** we performed a cross-sectional study among a Dutch, local GP network (n= 235), using a web-based digital survey. The survey contained multiple-choice questions about the delivery of palliative care and consultation practices.

**Results:** 119 surveys were available for analysis (50.6%). On average, GPs provide palliative care to a minimum of 6 patients per year and request, on average, consultation for 1 out of 3 palliative patients. GPs mainly consult informal caregivers (3.6 on a 5-point Likert scale), fellow GPs (3.3), homecare organisations (2.8) and the regional Palliative Care Consultation Team (2.6). Consultations mainly concern: physical symptoms (3.6), pharmacotherapy (2.9), and medical-technical procedures (2.9). Social and existential issues are infrequently addressed (both 1.9). Regarding their last palliative patient, 73% of the GPs requested a consultation. On average, 3.6 different persons or institutes were consulted (most common: fellow GPs, 68.7%) for 3.7 different topics (most common: physical symptoms, 70.1%). For most patients the first time of consultation occurred during the last month of life (58.2%).

**Conclusion / Discussion:** GPs mainly consult healthcare professional involved in community-based palliative care, or informal caregivers. Consultations mainly cover physical aspects of care and are mostly requested in the last month of life. Future research should focus on early timing of palliative care consultations and the attention given to existential and social issues.

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Abstract type: Poster

## Perceptions of Professional Caregivers of People with Intellectual Disabilities on Palliative Care

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**Background:** General practitioners, physicians and daily caregivers for people with intellectual disabilities (ID) are increasingly confronted with clients in need of palliative care. Previous studies have found that professionals in ID care services lack knowledge and experience concerning palliative and end-of-life care. It is not known however, how professional caregivers see and experience the concept of palliative care.

**Aims:** The purpose of this study is to gain insight in the perceptions that professional

caregivers of people with ID have regarding palliative care.

**Methods:** A semi-structured interview study was conducted among 18 physicians and 15 daily caregivers, who provide care to people with ID in the Netherlands. Topics included the definition of palliative care and (and barriers and facilitators for) early identification of the need for palliative care.

**Results:** All the aspects of the WHO-definition on palliative care are referred to by the respondents. However, the respondents focus on symptomatic/somatic care, psychosocial and spiritual care are less mentioned. In addition, palliative care is mostly associated with the diagnosis of an incurable disease and less to a gradual decline in health.

**Conclusions / Discussion:** This study shows that professional caregivers have a complete, but somewhat distorted, understanding of the concept of palliative care. However, in practice recognition of the need for palliative care in people with ID is often late in the end-of-life phase. These findings are important for the practice developments and education. Further research is needed to examine the barriers and facilitators in the delivery of palliative care to people with ID. In addition, it is interesting to examine the extent to which these results are representative for a larger group of professional caregivers of people with ID. In particular, to see if there are differences between caregivers with a medical background and caregivers with a background in social work.

Abstract number: P1-333

Abstract type: Poster

## Experiencing a Life Threatening Lung Disease - Qualitative Study with Patients at their End of Life

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**Background:** Diseases of the respiratory system are one of the most causes of death in Europe. Although some common patterns exist, patients' experiences of living with progressed lung cancer or COPD should be of greater interest.

**Aims:** To understand the meaning of living with these diseases and to contrast them in order to provide suitable palliative care.

**Method:** Qualitative longitudinal design to get a broad and deep insight into the patients' experiences. Over 12 month, 4 open guided interviews with patients (17 with lung cancer, 18 with COPD). Initial interviews were analysed using Grounded Theory (Strauss).

**Results:** Living with lung cancer means to redefine one's own being. This phenomenon seems to be the result of helplessness within the health system and is embedded with a shift of social roles. To reorganise daily life and to try to get expert of their own disease are main coping strategies. As a consequence, patients externally snap to attention and internally try to accept the threat. In contrast, living with COPD means to be at the mercy of the disease. Apparently, the main reason for this is a diffuse feeling of being ill because of slow progress and effective medication. COPD patients feel faced with their responsibility and have to cope with social isolation. As a main strategy, they try to maintain daily life as usual with the consequence of denying the threat to life as long as possible. For patients of both groups palliative care is strongly associated with immediate dying.

**Conclusion:** Being diagnosed with incurable lung cancer or severe COPD means to experience a decisive turning point in life, but at different times within illness trajectory. For both groups psychosocial support and early palliative care could help to relieve domestic burden. Family doctors and lung specialists, who are the primary carers for these patients, should assess and address the patients' palliative care needs and refer to palliative care specialists if necessary.

Abstract number: P1-334

Abstract type: Poster

## Exploring the Concept of Palliative Rehabilitation: The Active Palliative Rehabilitation in Lung Cancer (APRIL) Study

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**Background:** Evidence underpinning palliative rehabilitation is needed. APRIL was a six week home based intervention comprising physical activity (walking and muscle strengthening) and nutritional advice supported by weekly phone review and personalised goal setting. This intervention aimed to enhance quality of life, promote and maintain physical function and relieve dietary symptoms.

**Aim:** To develop and explore a novel rehabilitation intervention of physical activity and nutritional guidance for people with advanced inoperable non-small cell lung cancer (NSCLC) receiving palliative systemic therapy.

**Methods:** The MRC Framework for Developing and Evaluating Complex Interventions was used to design this multiphase mixed methods cohort study. APRIL was developed based on consensus agreement. EORTC QLQ-C15-PAL, MFI-20, PGSGA and functional outcome measurements (6MWT, STS60) were undertaken at baseline, intervention end and six weeks post completion. Semi structured interviews with patients and healthcare professionals (HCPs) explored experiences of APRIL; these were thematically analysed.

**Results:** Forty nine patients receiving palliative systemic therapy for NSCLC were screened February to December 2013. Of the 19 eligible patients, seven declined and one became ineligible pre consent. Two patients withdrew before week six and one before week 12 leaving a final cohort of eight. Qualitative findings are presented under the themes 'Living with and beyond an advanced cancer diagnosis: experiences of the APRIL Programme' for patient participants and 'Palliative Rehabilitation: exploring the concept' for HCPs.

**Conclusion:** The palliative rehabilitation approach of APRIL was valued by participants involved in this feasibility cohort study and HCP attitudes to palliative rehabilitation altered. Robust evaluation studies within this population are compromised by the ability to recruit sufficient numbers and with issues arising from missing data, response shift and attrition.

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**Abstract type:** Poster

## Cultural Awareness - Gaps and Views of Palliative Care Providers

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**Background:** Russian-speaking migrants (RSM) are one of the biggest migrant groups in Germany. Despite the numbers they rarely turn to palliative care services. This issue requires more systematic and 'in-depth' studies to identify the existing barriers for this group. Our study analyses the palliative care service utilisation by RSM in Germany and depicts their subjective demands to quality of life.

**Aims:** The major aim is to identify RSMs' needs and problems in their access to palliative care. Providers' views on culture-bound facets in the decision-making process and needs concerning quality of life shall be identified in order to reveal existing interculturally sensitive palliative care and barriers against using it.

**Methods:** The study analyses the perspectives of palliative care providers (35 semi-structured expert interviews), patients and relatives (around 30 semi-structured episodic interviews) on the conditions of palliative service utilisation and reasons of non-utilisation mentioned by each group. Data analysis focuses on determinants of utilisation behavior and aims at developing group specific typologies.

**Results:** Three practice patterns of experts become evident:

- (1) emphasising individuality independent from cultural background,
- (2) accepting cultural differences and using different ways of dealing with them and
- (3) reacting on cultural diversity only when it becomes a problem.

Different objectives of providers are evident: on one hand, to prioritise the equal treatment with better information about the concept of 'palliative care'; on the other hand a wish for (complementary) culture-specific offers, enabling further transfer of patients.

**Conclusion / Discussion:** Intercultural concepts dealing with the abovementioned challenges are still underdeveloped in Germany. It is important to raise the awareness for these problems as well as develop an integrative design concept enabling RSM to benefit from hospice and palliative services.

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**Abstract type:** Poster

## Assessing Albania Regional Hospitals Capacities Getting Started Palliative Care Service

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**Background:** Palliative Care (PC) is missing in health care sector (HCS) in Albania, meanwhile the demand for the service is growing up. There are estimated about 12.000 patients in need to PC per year. The government is aware to get started the PC service, but has limited financial and other resources. The budget of health sector is 2.9% of the GDP. Most cost effective strategy to integrate PC in public (HCS), is through regional hospitals (RH) because their low level of the bed occupancy (average 30%).

**Aim:** The aim of the study was to assess the human resource (HR), medicaments availability, infrastructure flexibility, equipments and capacities of RH to get started PC service.

**Methods:** Quantitative data on perception and attitude of health care professionals (HCP) on PC were gathered by a questionnaire delivered to 267 doctors and nurses in RH. Also, a semi structured interview with hospital administrators was used to collect secondary data/desk review from each of 11 RH in 2013. SPSS program (16.0) was used for the data analysis.

**Results:** Main findings shows that only 10.5% of HCP agree to provide PC in RH; 50% of hospitals provide only medical care; only 1.59% of HCP have participated in any kind of PC training; 18 from 34 medicaments of the essential list for PC are lacking in all RH; there is extremely low level of opioid availability and usage in all RH as well as a lack of basic PC equipments and materials. Most of RH in Albania have amount of space and medical HR needed for PC, but significant barriers exist concerning trained HR, medicaments, opioids and equipments availability as well as organisational flexibility.

**Conclusion:** Steps undertaken to get start PC service are, establishment the PC service in five pilot regions, theory and practical training of the pilot teams (PT), design the PC guidelines for (PT) functioning, lobby and advocacy with decision makers to improve the issues related with availability, access and usage of PC medicaments.

**Abstract number:** P1-337

**Abstract type:** Poster

## ACP CRIO: A Bold, Innovative Knowledge Translation Research Program Studying a Province-wide Implementation of Advance Care Planning and Goals of Care Designation

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Advance Care Planning (ACP) is a process of reflection on and communication of a person's future healthcare preferences. ACP encourages dialogue between a patient, his/her family, and the healthcare team that can guide medical decision making even when a person becomes incapable of consenting to or refusing healthcare. ACP programs and policies are being implemented across healthcare systems around the world including in Alberta, Canada.

Alberta Health Services (AHS) is the major publicly funded comprehensive health care organization for the four million residents of the province of Alberta. 'Goals of Care Designation' is a made-in-Alberta medical order used by healthcare providers to describe and communicate the general aim or focus of care. In 2014, AHS implemented a multi-sector, provincial policy for ACP/GCD across all AHS facilities. ACP CRIO is a bold, innovative knowledge translation research program that has partnered with AHS to prospectively study the system-wide uptake of ACP/GCD, and its impact on the healthcare system. Five-year funding for ACP CRIO is from Alberta Innovates - Health Solutions' Collaborative Research and Innovation Opportunities (CRIO) competition.

ACP CRIO's purpose is to determine *how to optimally implement* a formalised ACP framework across a large population and throughout a complex, multi-sector healthcare system. We have applied the knowledge-to-action cycle to support adoption and use of ACP/GCD across Alberta, through four research activities designed to identify:

- (1) Local barriers and facilitators to uptake of ACP/GCD;
- (2) Effective tools for *education* and *engagement* of stakeholder groups in ACP/GCD, adapted to the local environment;
- (3) Informative *indicators* to monitor uptake of ACP across the healthcare system, and how they can guide continuous improvement of the ACP implementation strategy;
- (4) Economic *consequences* of ACP implementation. Preliminary outcomes from this program of research will be presented.

**Abstract number:** P1-338

**Abstract type:** Poster

## Factors Associated with Increasing Public Participation in Advance Care Planning in Alberta, Canada

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**Background:** Advance Care Planning (ACP) encompasses both verbal and written communications expressing preferences for future health and personal care and helps prepare people for healthcare decision-making in times of medical crisis. Governments and healthcare systems are increasingly promoting ACP as a way to inform medical decision-making but it is not known whether public engagement in ACP activities is changing over time.

**Methods:** Raw data from two independently conducted public polls of ACP engagement over a 6-year time period were analysed to answer:

- (1) Did participation in ACP activities change over time?
- (2) Did intra-provincial variation in ACP health system policy explain differences in engagement?

**Results:** Statistically significant increases were observed between 2007 and 2013 in: recognising the definition of ACP (54.8% to 80.3%, OR 3.37 (95% CI 2.68-4.24)), discussions about healthcare preferences with family (48.6% to 57%, OR 1.41 (95% CI 1.17-1.69)) and with healthcare providers (9.1 to 17.9%, OR 1.98 (95% CI 1.51-2.59)), written ACP plans (21 to 32.1%, OR 1.77 (95% CI 1.45-2.17)) and legal documentation (23.3 to 39.3%, OR 2.13 (95% CI 1.75-2.59)). These remained significant after adjusting for age, education and self-rated health status. Public participation in ACP could not be explained through intra-provincial variations in ACP policies.

**Conclusion:** ACP engagement is increasing over time, although the overall frequency remains low. Examination of factors responsible for the increase may provide insight into areas for future investment. We also discuss potential reasons why health system policy presence alone may not influence public participation.

**Abstract number:** P1-339

**Abstract type:** Poster

## Barriers in Access to Basic Palliative Care for Cancer Patients in the Community

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**Background:** In 2013 in Romania specialised palliative care (PC) services covered around 6% of patients in need. A Romanian Swiss joint project was developed to pilot basic PC in community for cancer patients based on GP's as the largest medical network.

**Aim:** To understand the gaps and barriers in the clinical, educational, legal-organisational and financial domain that that would hinder the implementation of basic palliative care in the community through GPs.

**Method:** Qualitative study using case studies (CS) and focus groups (FG) as data collection tools. Regional meetings were conducted in 4 pilot areas in Romania with GPs, nurses, oncologist, health authorities, and patients' representatives to collect CS on a template with open questions concerning the 4 domains. The themes from the CS were used to develop the interview guides for the FG. FG were organised with patients, families, bereaved families, doctors, nurses and social workers. Open coding by 2 researchers.

**Results:** 77 CS and 10 FG were run. Main barriers,

**Clinical domain:** Lack of clinical protocols; insufficient screening /management of symptoms; futile treatments at end of life; communication difficulties with patients, families and between professionals (collusion being a major problem), no care coordination.

**Educational needs:** Pain management; invasive procedures; communication; terminal care.

**Financial domain:** Underfinanced health care system, family members leave job to provide care, reimbursement problems for procedures and drugs in the community.

**Organisational area:** Reduced GPs home care visits, need of call centre for GPs for difficult PC cases, no morphine in GPs emergency kit, opioids not in all pharmacies, no transport of staff in community, no coordination GP- hospital for discharge, variable interpretations of law/ regulation.

**Conclusion:** several barriers identified in all 4 domains. Alongside education and development of care protocols advocacy will be needed to adjust restrictive policies.

**Abstract number:** P1-340  
**Abstract type:** Poster

## Coordinating and Integrating Palliative Care and Rehabilitation - Why, When, and How?

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**Background:** The Danish National Board of Health recommends further coordination and integration of palliative care (PC) and rehabilitation (R). PC and R in a Danish context are more frequently separately organised than in comparable countries e.g. UK. In this study we reviewed the international literature on relations between PC and R in order to provide a knowledge base for carrying out the recommendations.

**Aim:** A qualitative review was conducted to provide evidence about interfaces and coordination and integration of PC and R.

**Methods:** Medline, Cinahl, Embase and PsycINFO were searched for articles concerning both PC and R associated with cancer, lung disease, neurologic disease and disease in the elderly, published between 2003 and 2013 inclusive. As high strength intervention studies in this field are rather scarce, articles concerning the relation between PC and R were selected and analysed within a narrative review framework.

**Results:** 110 articles were selected and analysed and six themes were constructed, answering the question of why, when and how PC and R should be coordinated and integrated: Reviews and their focus; Evidence and strength of evidence; Cultural challenges; Target groups and phases; Arguments to support further coordination; and Patient-perspectives.

**Conclusion / Discussion:** Though the evidence based on intervention studies is weak, the narrative review provided a balanced knowledge to guide and support clinical practice in developing a dynamic interface between palliative care and rehabilitation.

**Abstract number:** P1-341  
**Abstract type:** Poster

## Don't Forget Sexuality: A Study on Responses of a Group of Palliative Care Operators

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**Background:** Literature shows a lack of studies focused on the sexuality of palliative care patients. The few studies on the subject depict a situation where great difficulties are encountered by operators in recognising sexuality as a need of the patient, and in talking about it. For this reason, we decided to interview palliative care operators about sexuality. The foundation we are working for is a charity that provides specialist palliative care to severely ill patient and their families. It has a home care team and two hospice inbed facilities. Overall the service looks after 1300 patients per year.

**Aims:** This study aims at investigating how operators in our specialist palliative care team approach the need of sexuality in their assisted patients.

**Methods:** A semi-structured interview has been used as survey tool. The interviewees are chosen among professionals involved in the different services of the charity, stratified according to job, age, gender and prevalent work setting. The recruitment of the interviewees has been initially performed on a voluntary basis. The sample was not defined 'a priori', but the final number of interviews will be decided when a saturation of the data will be achieved. Data analysis is being conducted using a content analysis of the main emerged themes. To date 3 interviews have been completed and ten more are scheduled to be performed in the next weeks.

**Results:** Early results show recurring problems, particularly the difficulty in talking about the sexuality not only with the patient but also with the colleagues. The interviewees agree in saying that speaking is the first step to defeat sexuality taboo. In most cases the first response to the need for sexuality is listening and all the interviewees believe it is important to refer to an expert in this field to adequately respond to this need.

**Conclusion:** Complete results will be presented within the congress.

**Abstract number:** P1-342  
**Abstract type:** Poster

## Family Caregivers' Perspectives on Hospice Day Care from a Retrospective Survey in Austria

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**Background:** Supporting family caregivers is one of the central aims of hospice day care. This is usually achieved by relieving carers for at least one day a week. This is complemented by other interventions and activities of hospice day care like counselling. Although numerous international studies to evaluate hospice day care have been done, very few and mainly qualitative studies provide evidence based on family carers' perspectives.

**Aim and method:** The aim of this study was to evaluate a hospice day service in Austria including the perspective of bereaved family carers. For this, a retrospective postal survey-design was chosen, covering all users of the day hospice back to three years (n= about 220). The questionnaire focussed on family carers' views on effects of hospice day care on place of death, social inclusion and symptom management of the patient, as well as on issues of personal support of family carers. Descriptive analysis and correlation were performed using SPSS.

**Results:** 42% of the questionnaires did return (n=42) and provide the basis for analysis. Aside from a gender bias, the sample reliably represented the structure of day hospice users. 44.7% of the users attended the day hospice once a week. We found evidence that hospice day care provided relief for family caregivers in the following aspects: Very time-consuming care work was reduced by 20%, support with symptom-management and the availability of information on specific treatments or problems (94.8% were most satisfied with the latter). 74% agreed that hospice day care allowed the deceased patient to stay at home longer.

**Conclusion:** The high concordance between needs and service provision and the satisfaction with the most important aspects of bereaved family carers with hospice day care

may not surprise at all, but underlines how much this kind of service fills a gap in the health care system which produces stress for family care.

**Abstract number:** P1-343  
**Abstract type:** Poster

## Do Engaging with Social Media Benefits Hospices? Case Study Analysis of Four UK Hospices

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**Background:** Emerging evidences suggest that use of Social Media helps to share information and resources and reach intended and 'beyond' audiences with quick and fast manner. Currently, hospices around UK and world actively engaged with social media with different purposes. Yet, little is reported around the role of social media and its benefits for hospices.

**Aim:** To investigate the use, engagement and the reach-out of social media among four hospices in the UK.

**Methods:** A qualitative case study approach was adopted; studying purposeful sampling of four social media engaged hospices within UK. Data collection used multiple methods to collect publicly available data that include feeds, comments, shares, tweets, status updates from two online social networking sites namely Facebook and Twitter of selected hospices. Using Nivio10<sup>®</sup>, a thematic analysis was undertaken.

**Results:** Analysis of data found that all the hospices were actively engaged mainly in four different activities; fundraising, sharing best clinical practices, promoting educational activities, and advertising jobs. Hospices also involved in community outreach activities by celebrating local events and cultural and religious celebrations.

**Conclusion:** Findings indicate that engagement with social media enable hospices to remain in 'core businesses' of running with local support. Yet, Hospices could be more explicit in sharing about how well it benefits for patients and carers that could enable access to hospice services across the diverse population by sharing stories of hospice patients and relatives' experiences.

**Abstract number:** P1-344  
**Abstract type:** Poster

## Quality of Life, Symptom Burden and Satisfaction with Care among Older Latinos with Advanced Cancer

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**Context:** Research on the factors influencing the quality of life among older Latinos with advanced cancer has been limited.

**Aims:** To identify the demographic, clinical, psychosocial and health system-related factors associated with quality of life (QOL) in a cohort of older Latinos with advanced cancer.

**Methods:** Older Latinos with advanced cancer enrolled in a longitudinal study completed interviewer administered baseline surveys which included measures of QOL (FACT-G), functional status (ECOG), symptom burden (ESAS and EQ-5D), as well as demographic, psychosocial and quality of care measures. Analyses of variance (ANOVAs) were conducted to identify factors associated with QOL.

**Results:** Seventy-nine baseline interviews with advanced cancer patients were completed. Sixty-one percent reported being 'very much/quite a bit'; 20% 'somewhat' and 19% 'not at all/a little bit' content with the current quality of their life. Pain, fatigue, depression, anxiety, shortness of breath, appetite, ECOG status and problems with mobility, self-care and usual activities were all independently and significantly associated with reduced QOL ratings (P< 0.04). Higher satisfaction with care scores were associated with higher QOL scores (P= 0.013). Patients reporting having a living will were also more likely to have lower QOL scores (P = .011).

**Conclusion:** Findings suggest that physical and psychological symptoms are significantly associated with QOL in this population. The associations between QOL and satisfaction with care and living wills may suggest that patients who are less satisfied with their care and those with living wills may have higher symptom burden and consequently reduced QOL. Further research is needed to identify predictors of QOL by clarifying the directions of the associations to identify specific areas of intervention for improving the care provided to, and QOL of, this vulnerable population.

**Abstract number:** P1-345  
**Abstract type:** Poster

## Days of Dying - Are Patients on a Palliative Care Unit Die on Certain Days?

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**Aim:** Frequently people working on a Palliative Care unit have the impression that patients are dying on the weekend. However, it has never been analysed if there are certain days on which people on a Palliative Care unit are dying. Therefore, we retrospectively have analysed the days on which patients have died.

**Methods:** Retrospective analysis of days in the week on which patients have died on the Palliative Care unit of a university hospital in the years 2005 - 2011. We have used the electronic files of the hospital and have manually evaluated the day of death.

**Results:** Within the years analysed frequently more than 100 patients have died annually (2005: 100; 2006: 159; 2007: 157; 2008: 161; 2009: 144; 2010: 152; 2011: 176).

The deaths occurred most frequently on fridays in the years 2005 (18%), 2006 (21%), 2007 (18%) and 2009 (22%). In 2008 the day most patients died has been monday (19%), in 2010 it has been wednesday (16%) and in 2011 it has been sunday (17%).

Patients were less likely to die on sunday in 2009 (6%) and 2010 (12%), on thursday in 2006



(11%) and 2011 (10%), on Monday in 2005 (8%), on Tuesday in 2007 (8%) and on Friday in 2008 (10%). There has been no statistical significant difference between the days. We have not been able to recognise any particular circumstances of the differences regarding the days on which patients have died. **Conclusion:** Our data show that patients over the years have died most often during the week and not on the weekend. Over the years the day most patient have died has been Friday.

## Policy

**Abstract number:** P1-346  
**Abstract type:** Poster

### The Norwegian Pilgrimage: Raising Public Awareness on the Human Right to End-of-Life Care

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**Aims:** To present the experience of raising public awareness on the human right to a dignified death through the organisation of a pilgrimage, which used the 'camino' as a symbol to communicate the pathway to palliative/hospice care.  
**Background:** Although Norway scores high in the Global Atlas of Palliative Care at the End of Life (level 4b): Advanced health system integration, dignified dying conditions and evaluation of available palliative care services are lacking. Worries about end-of-life care are increasingly expressed; patients are being moved from service to service. Home as a place to die: just 14.5% in 2012. Death and dying have been subjects of increasing concern to Norwegians, however policies to meet the needs of the dying and the bereaved are still underdeveloped.  
**Approach taken:** A pilgrimage was organised, to raise public awareness on palliative/hospice care. It involved 40 days of walking and invited people and professionals to join parts of the trajectory. Activities were organised at specific sites which aimed at an open dialogue with the public on the principles and values of palliative care which are associated to the roots of hospice. A website for information was made and a collaborative alliance was established with the media.  
**Results:** The use of the 'pilgrimage' as an innovative method to raise public awareness has proved to have several benefits at a local and national level:  
(a) rich interactions with people on the pathway  
(b) media attention on a local, national, and international level;  
(c) participation of health care professionals, exchange experiences and shared vision; and  
(d) collaboration with the Minister of Health, who joined the pilgrimage, for the revision of the Norwegian legislation on palliative care.  
**Lessons learned:** The possibility of raising public awareness and advocating for palliative care as a human right through the organization of pilgrimages in European countries and internationally will be discussed.

**Abstract number:** P1-347  
**Abstract type:** Poster

### Collaboration of Ngo's and Government of Ukraine for Development of Palliative and Hospice Care Regulatory Basis

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NGO 'Ukrainian League for Palliative and Hospice Care' (League) started preparations for the Second National Palliative Care Congress, scheduled for September, 2015. Hence, we constantly analyse the implementation of 'National Strategy for Development of Palliative Care in Ukraine to 2022' (Strategy), which was approved at the First National Palliative Care Congress, hosted by League on September 26-27, 2012 in Kiev.  
One of the Strategy's priorities is regulatory basis development. Due to League's lobbying and collaboration with the Government, the Parliament Law of July 7, 2011 'On Amendments to Fundamental Principles of Legislation of Ukraine on Health Care' which defined Palliative and Hospice Care (PHC) as a separate type of health care and a few PHC regulatory acts were implemented. Ministry of Health of Ukraine (MOH) Order №41 of 21.01.2013 'On Palliative Care Establishment' is a fundamental step in developing of effective and accessible system of PHC in Ukraine. Ministry of Social Affairs and MOH of Ukraine a joint Order №317/353 of 23.04.2014 'On approval of liaison protocol between subjects engaged in the provision of social palliative care services at home for the terminally ill' will help to improve inter-agency cooperation in outpatient PHC. MOH Order №77 of 01.02.2013, permitted to use morphine tablets; MOH Order №311 of 25.04.2012 approved a Clinical Protocol for Chronic Pain Syndrome Care and Cabinet of Ministers Decree № 333 of 13.05.2013 concerning of narcotic drugs, psychotropic substances and precursors in health care institutions facilitated the availability of PHC patients with chronic pain to effective pain relief, especially in the outpatient facilities, improved quality of life of the terminally ill and their families.  
The League understands problems and challenges that Ukraine should be solved for creation of accessible PHC system. League can promote it through the involvement and cooperation of community, specialists and Government.

**Abstract number:** P1-348  
**Abstract type:** Poster

### The Effects of a Promotion Software System for Hospice Shared Care Consultation in a Regional Hospital in Southern Taiwan

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**Purpose:** Hospice shared care is a connection from original team to palliative medicine team. However, patients and families are not willing to receive palliative care till patients in the end of life in Asia. According to our national policy and world trend, our aim is to create and evaluate a promotion software system for hospice shared care consultation.  
**Materials and methods:** We start a promotion software system between 2014/2 to 2014/5. The subjects are  
(1) ICD 9 code stage belong malignant neoplasm, stage 3 and 4;  
(2) patient whom had not been received hospice shared care in the past 6 months.  
The promotion soft system of hospice shared consultation hint is revealed on the screen when doctors prescribe medicine order. Moreover, the doctors of original team can decide consult hospice shared care or not after consideration and discussion with team and family. We recorded the numbers of consultation during 2014/2 to 2014/5.  
**Results:** Compared with the numbers of consultation during 2013/2 to 2013/5, the total numbers of consultation during 2014/2 to 2014/5 was increased from 44 (20.7%) to 104 (35.5%). The top three original team whom care stage 3 and 4 cancer patients are oncology (81), general surgery (66) and chest (47) department, while the top three rate of consultation from original team are hepatobiliary (55.0%), oncology (48.1%), chest (46.8%) department. However, original team and patients are more and more willing to receive hospice shared care after the system promotion.  
**Conclusion:** Although the result are not achieved our goal yet (consultation rate of stage 3 and 4 cancer over 50%). After the new promotion system for hospice shared care consultation intervention, it had positive effect on increasing consultation rate and build a connection between original team and hospice care.

**Abstract number:** P1-349  
**Abstract type:** Poster

### We Are the Champions: How European Awardees of the International Pain Policy Fellowship Have Improved Opioid Availability and Accessibility in Europe

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**Aims:** Relieving severe pain, a critical component of palliative care, cannot be accomplished without improving availability and access to opioid medicines. Many factors contribute to inadequate pain relief globally. In Europe, some countries lack national formularies that include opioids indicated to treat moderate or severe pain, require physicians to have special prescription authority, require special prescription forms, and impose strict limits on amounts or durations.  
The International Pain Policy Fellowship (IPPF) program is designed to empower champion change-agents from low- and middle-income countries to work with their governments to evaluate and implement system and policy changes to make opioid medicines available for patients receiving palliative care services. Three cohorts of health professionals and health regulators have been awarded Fellowships in 2006, 2008, and 2012. The objective of this study is to describe the progress to date of 7 Fellows from 6 European countries (Albania, Armenia, Georgia, Kyrgyzstan, Serbia, and Ukraine) resulting from the IPPF program.  
**Methods:** All Fellows attended a week-long training session to learn about the roles and functioning of the international drug control system and to create a national Action Plan to improve opioid availability in their country. For the remaining Fellowship period, international experts provided technical assistance to the Fellows to implement their Action Plans.  
**Results:** Fellows, collaborating with government officials and colleagues in their countries, made notable progress in the areas of national and opioid policy, distribution, availability, education, and cost.  
**Conclusion:** The IPPF has empowered highly-motivated health professionals as champions to work with mentors and colleagues, resulting in significant progress towards overcoming barriers to opioid availability in their countries.  
**Acknowledgments:** Open Society Foundations, Livestrong, US Cancer Pain Relief Committee.

**Abstract number:** P1-350  
**Abstract type:** Poster

### Possibilities of Implementation Palliative Care to Children with Limited Resources (The First Children's Hospice in Ukraine)

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**Introduction:** Subject creating children's hospice was discussed in various circles of civil society. We made analysis of child morbidity. It showed that is registered for 400-500 children with severe incurable diseases in an average year, including 100-120 - cancer patients. The district pediatrician is not always able to provide full medical care in accordance with all components that provides palliative care.  
That was what we followed in determining the need for opening children's hospice and advocacy issues in different structures of government and civil society.  
The purpose of the article: we showed how it is possible - step by step - to create of children's



hospice in light of limited resources, but the combined participation of government, NGOs and civil society in the region.

**Methods:** Opening children's hospice preceded by preparation: the order of the regional health department, training in children's hospices Belarus, Poland, Russia; inclusion in a comprehensive program 'Public health Carpathian 2013-2020'; discussion and debate with the public to find resources; moral, material, financial, publication in all media, social networks, websites hospice; 5-hour TV marathon 'Live and Believe'. An important element of the goal became constant monitoring and control of all public funds flow, repair and reconstruction of buildings.

**Main results:** All previous initiatives and activities allowed to collect donations of more than 1.5 million UAH; for 9 months made a reconstruction of the premises; December 21, 2013 the official opening of the first in Ukraine children hospital palliative care 15 beds.

**Conclusions:** Activation of society and cooperation between authorities and communities, openness and transparency of all processes allowed to solve the difficult problem to create a children's hospice in light of limited resources.

**Abstract number:** P1-351

**Abstract type:** Poster

### IAHPC Advocacy for a Human Right to Palliative Care

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**Hypothesis:** UN member states (MS) will resolve that palliative care is a human right (HR) once they are convinced that the social, political, and economic benefits of doing so outweigh the costs re national public health and development outcomes. Representatives of MS in UN institutions and treaty bodies are largely unaware of the unmet need for palliative care in their countries. Global advocacy for a HR to palliative care will introduce the palliative care narrative to the language of international human rights diplomacy, improve awareness of the global deficit of services, and draw attention to the lack of access to opioid medicines for pain relief in more than 80% of UN MS.

**Methodology:** Active participation as a representative of IAHPC at sessions of UN treaty bodies, functional organisations and specialised agencies. Review of multi-lateral treaties and international law implicating palliative care and access to opioid medicines. Extensive collaboration with global palliative care leaders and partners in country.

**Discussion:** Various articles in prestigious journals, as well as civil society/professional organisation 'declarations' and manifestos, have proclaimed that access to palliative care is a HR. Just saying something is a human right does not make it so, however. Enforceable human rights entail the passage of resolutions either at the Human Rights Council or UN General Assembly that recognise MS's binding obligation to ensure the right. In times of national and global uncertainty and budget scarcity, even sympathetic MS are reluctant to assume new obligations to give citizens new services having unknown policy benefits.

**Conclusion:** Progressive development of a multi-level strategy creating dynamic, mutually reinforcing communications networks linking local, national and regional partners with representatives of UN agencies and treaty bodies, will create positive policy space for the passage of a resolution commanding widespread MS support within 5 years.

**Abstract number:** P1-352

**Abstract type:** Poster

### Advance Care Planning - The New Establishment Paternalism?

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**Background:** Advance Care Planning (ACP) is being promoted as a way of extending individual autonomy into future states of loss of Mental Capacity by participation in decision making about end of life care. In England, it is the Physicians or Specialist Nurse who initiates the discussion. Increasingly ACP is enshrined in policy in the health service.

**Aim:** This study considers whether despite the good intentions, as ACP is implemented, there are risks that this becomes a new establishment paternalistic approach to managing patients at the end of life

**Methods:** Reflection on concepts of autonomy and paternalism within the context of Advance Care Planning in the UK using case histories.

**Results:** ACP is based on a medical model and primarily concerned with decisions about medical care. Here will always be a fundamental imbalance in medical knowledge between the medical practitioner and patient and this can lead to dominance of the medical view. As with all policies there are risks with implementation and case studies reveal that for example the '1% campaign' which encouraged GPs to identify the 1% patients entering their last year of life led some GPs to inform patients of their imminent risk of death and need for ACP without testing carefully if the patient wanted such a discussion. Cancer patients undergoing palliative surgery are furious at being asked whether they want to select a Do Not Attempt Resuscitation (DNAR) during pre-operation. Care Homes are being encouraged to implement ACP and relatives of elderly patients are asked to tick the boxes for DNAR when the patient is admitted.

**Conclusion:** At its most fundamental ACP is a paternalistic model designed by the medical profession and focussing on medical. As ACP is implemented it becomes more professionalised and routinised. There are even greater risks of establishment paternalism if other policies such as reducing emergency admissions and length of hospital stays can be linked to ACP as a route to achieve targets.

## Public health and epidemiology

**Abstract number:** P1-353

**Abstract type:** Poster

### The Model of Advanced Care Planning in Catalonia (Spain)

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**Background:** Care models for advanced chronic patients present two key aspects: early identification and advanced care planning (ACP). In 2012, Catalonia implemented the Care Model towards chronic diseases and the Model of ACP was developed in 2014.

**Aims:** Describe the implementation process of the Catalan Model of ACP.

**Methods:** A core group of professionals was convened to develop the model of care.

Inclusion criteria included: solid professional trajectory, homogeneous representation as for territory and professional profile, personal interest in the subject, and co-participation of patients, caregivers and family, social agents and healthy persons.

Four work levels were defined: elaboration of a conceptual document (CD) and the implementation guide (IG), development of the implementation training program (ITP), building-up of discussion groups (DG). Moreover, four work groups were established for each of the defined work levels. Their involvement in the project was based on their real availability and area of expertise.

The CD is the first work level developed. In parallel, the DGs of patients, professionals and healthy persons are established so as to make the CD a work product of high quality.

**Results:** 55 professionals participated. At the first phase, the CD was written with the agreement of expert professionals (n=26) in legislation ethics, medical specialties, nursing, anthropology, social work and psychology. The document justifies and argues the need for systematic ACP implementation in the current Catalan model of care.

During the second phase, the IG and the ITP are being created, as key aspects of the implementation process.

**Conclusions/discussion:** ACP is a challenge for the model of care towards advanced chronic patients. The Catalan Model of ACP establishes the conceptual and pragmatic foundations of ACP and promotes the training of the professionals daily taking care of such type of patients.

**Abstract number:** P1-354

**Abstract withdrawn.**

**Abstract number:** P1-355

**Abstract type:** Poster

### Are Quality of Life Scores Biased in Units with Low Response Rates? Data from the Danish Palliative Database

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**Background:** In studies with low response rates it is important to study if the data are valid or might be distorted by selection bias. This study includes data from all Danish specialised palliative care (SPC) units with different response rates on a questionnaire on symptoms/problems and quality of life (QOL). Particularly units with low response rates may be prone to selection bias if e.g. only the patients feeling the best answered.

**Aims:** To study whether selection bias was present in SPC units with low response rates.

**Methods:** Information on 9 symptoms/problems and QOL from the EORTC QLQ-C15-PAL questionnaire have been collected in the Danish Palliative Database on 12,288 cancer patients at the start of SPC. Linear multiple regression analyses was performed to test if response rate was associated with the symptom/problem/QOL scale scores. A specific-unit-random-effect was included

to account for that patients from the same unit were expected to be more alike than patients from different units. Binary logistic regression with random effects was used to verify the results for the single item scales.

**Results:** The overall response rate was 49% but varied between year and unit from 0-94%. The response rate was unrelated to 7 scales and significantly associated with 3 (dyspnea, appetite loss, physical function) scale scores. In these cases, the effect of response rate was low, even where the response rate was less than 20% (up to 7 on a 100 point scale). The results in the linear regression analyses were supported by the logistic regression analyses.

**Conclusion / Discussion:** Our hypothesis of selection bias with higher scores in units with low response rates was not supported. Therefore there does not seem to be any reason to exclude data from SPC units with low response rates.

**Abstract number:** P1-356

**Abstract type:** Poster

## Predictive Factors of the Place of Death among Cancer Patients after a Multidisciplinary Evaluation Carried out by a Supportive Palliative Care Team in Catalonia

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**Background and aims:** Most patients with cancer prefer to receive care and die at home. Also dying at home can be considered an outcome of high quality palliative care. However, in developed countries more than half of patients with advanced cancer die in the hospital setting. In our area, little is known about patient's preferences regarding the place of death (PoD). As a quality outcome we define the PoD as the place where, after an intensive multidisciplinary evaluation and an agreement with both patients or relatives, the discharge is planned. In this study we aim to know the effectiveness of the evaluation carried out by the supportive palliative care team (SPCT) at the HUAV of Lleida and evaluated with the % of patients dying at the final place agreed (acute hospital, home and in-site palliative care unit). **Methods:** We conducted an observational cohort study to identify the PoD of patients discharged from the SPCT at the HUAV of Lleida between 2010 and 2012. Inclusion criteria included those advanced cancer patients discharged to our influence area where different levels of palliative care are provided. We use univariate analysis (chi-square test) to determine statistical significance. Values of  $p < 0.005$  were considered significant. **Results:** 1179 patients met the inclusion criteria. 574 (48.7%) were discharged at home; 290 (24.6%) were discharged to the acute hospital and 315 patients were discharged to a palliative care unit (26.7%). Statistical significant differences were found between the place of discharge and the PoD ( $p=0.000$ ), marital status ( $p=0.000$ ) the lack of identified carer ( $p=0.001$ ) and younger ages ( $p=0.000$ ). Gender and cancer type did not reach statistical differences.

**Conclusions:** A careful multidisciplinary evaluation will lead to a great effectiveness when deciding the place where the patients are going to be cared for. Young, divorced, with no carer identified and living in bigger cities were prone to die in the acute hospital.

**Abstract number:** P1-357

**Abstract type:** Poster

## Information Technology and Cancer Patient Reported Outcomes

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**Introduction:** Patient Reported Outcome (PROs) refers to self-reported symptoms, health status measures and quality of life (QoL). They are valid for clinical care and research. Tablet computers (TC) may help collect data. We report cancer PRO's collected by TC.

**Methods:** We conducted a retrospective cohort study (2012-2013) of a cancer data registry of outpatients at a tertiary academic medical centre. Demographic and disease related variables were extracted from comprehensive electronic medical records. Those  $\geq 18$  years with a histologically confirmed cancer diagnosis were included. European Quality of Life (EQ5D), Emotional Thermometers (ET) and Functional Assessment of Cancer Therapy Scale - General (FACT-G) were collected via TC. Bivariate analysis and linear/logistic regression analysis were done.

**Results:** N=1157 outpatients completed their first assessment via TC. Mean ( $\pm$ SD) age was 58.4 ( $\pm$ 13.6) years. Most were Caucasian. About half were on private and one third on public health insurance. A high physical and psychosocial symptom burden was noted. Breast cancer was commonest. Bone was the most common metastasis. 55% had pain/discomfort 44% were moderately or severely anxious/depressed, 35% had mobility problems, 7% required help completing the survey. Those with EQ5D Anxiety/Depression - scored 1.7 higher for Distress (Coef: 1.7;  $p < 0.000$ ), Anxiety (Coef: 2.4;  $p < 0.000$ ), and Depression (Coef: 2;  $p < 0.000$ ) in ET.

**Conclusions:**

1. Physical and psychological distress was highly prevalent in a large cancer data set; during cancer treatment. More than half had pain/discomfort.
2. Emotional and mental health domains were inter-related.
3. ET components were consistently associated with EQ5D dimensions.
4. Those who were single, ethnic minorities or with private insurance had greater psychosocial distress.

**Abstract number:** P1-358

**Abstract type:** Poster

## Generalist Primary and Palliative Care is Associated with Few Hospitalisations in the Last Month of Life

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**Background:** Hospitalisations in the last phase of life may be related to poor quality of palliative care at home. In the Netherlands, that has a generalist palliative care model, palliative care at home can be given by generalist and palliative care consultants.

**Aim:** To study the association between provision of primary and palliative care at home and hospitalisations in the last phase of life in the Netherlands.

**Methods:** We conducted a cross sectional survey among Dutch general practitioners (GPs) on their most recent patient that died non-sudden. Of 1601 eligible GPs, 598 responded (37%). Questions were asked on (timing of) hospitalisation and on elements of primary care,

generalist palliative care and consultation of specialised palliative care. The relation between these elements and hospitalisation were tested controlling for patient characteristics.

**Results:** Two primary care elements were related to both not being hospitalised in the last week of life and not being hospitalised in the last month of life: having more GP visits two to three months before death (OR=2.64 and OR=2.37) and information transfer to out-of-hours GP services more than one week before death (OR=2.02 and OR=1.64). The two palliative care elements studied were only associated to not being hospitalised in the last month of life: recognising that death was near earlier (OR=1.75) and having palliation as the main treatment aim (OR=2.34). Consultation of a specialised palliative care professional in the last three months of life, was not found to be associated with not being hospitalised.

**Discussion:** Our results show that generalists, especially GPs, can play an important role in providing palliative care at the end of life, when looking at hospitalisations as indicator of quality. This suggests that a generalist palliative care model is feasible.

**Abstract number:** P1-359

**Abstract type:** Poster

## Variation of Intensive Care Utilisation at the End-of-Life in Patients Dying from Chronic Non-cancer Disease versus Cancer: A Nationwide Cross-sectional Study

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**Background:** Intensive care is often provided towards end-of-life (EOL), occupying extensive resources and causing emotional burden for patients and relatives while not necessarily aligning with their preferences.

**Aim:** To examine if age, gender and underlying chronic disease predict use of intensive care at the end-of-life.

**Methods:** Nationwide historical cross-sectional study of all adults dying of either cancer or chronic non-cancer (NC) disease (Diabetes, dementia, ischemic heart disease, heart failure, chronic obstructive pulmonary disease (COPD), stroke, and chronic liver failure) in Denmark from 2007-2011. Using the Danish Intensive Care Database, we identified all admissions to intensive care units (ICU) the last 6 months before death and place of death. We calculated the proportion of patients admitted to ICU and compared adjusted risk ratios (aRR) for ICU admission according to age, gender and underlying chronic disease (cancer and NC disease).

**Results:** Overall, 12.3% of NC patients were admitted to an ICU within their last 6 months compared with 8.7% of the cancer patients. Overall aRR for ICU admission at EOL in NC patients was 2.11 (95%CI:1.98-2.24) compared with cancer patients. However, high variation was seen, i.e. patients with dementia had an aRR of 0.19 (95%CI:0.17-0.21) and patients with COPD an aRR of 3.19 (95%CI:2.97-3.41) for ICU admission, compared to cancer patients. Among patients aged 90+, NC patients were less likely to be admitted to an ICU compared to cancer patients (aRR women 0.60(95%CI:0.50-0.73), aRR men 0.85(95%CI:0.65-1.11)) Overall, death in ICU was more common in NC compared to cancer patients (aRR=1.23(95%CI:0.99-1.54))

**Conclusion:** The remarkable variation in use of intensive care at EOL in patients with chronic diseases warrant further investigation into the interaction between patients' needs and preferences and prioritisation of health care resources.

**Funding:** Foundation of 17-12-1981 and the Danish Heart Foundation.

**Abstract number:** P1-360

**Abstract type:** Poster

## Quality of Death and Dying - 75 Advanced Cancer Patients' Dying Experience from the View of their Family Members

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**Background:** Advanced incurable cancer patients' (pts) dying experience varies and is influenced by many factors (place of death, access to care, type of cancer, psychological burden).

**Aims:** To investigate the QODD of advanced incurable cancer pts from the view of a proxy and to assess determinants of better/worse QODD.

**Methods:** The QODD was formally translated, validated (2 centres, 14 proxies) and adapted in Romanian and German language.

The reported data is part of a larger study (268 advanced cancer pts, defined palliative care (PC) needs, (74% ECOG 1+2), monthly collection of pt perceived needs/recalled delivery by hcp for 7 PC key interventions, demographics (adapted EAPC dataset), PC needs (IPOS), QoL (EQ5D), and quality indicators (QI, inappropriate anticancer treatment, aggressive end-of-life care, and QODD). For the QODD, a proxy was interviewed 6-12 weeks after death in person or by phone. By the interview caused distress was assessed.

**Preliminary results:** 75 QODD were available end October 2014. QODD score (0 worst, 100 best) was 65 (mean). The different centers (3 cancer centers, 1 district hospital, 1 hospice) varied in the mean scores between 49 and 78. Home was the most common place of death (53%, mean QODD 63) followed by PC unit (20%/72), hospice (9%, 69) and oncology ward (9%, 60). QODD score was not influenced by distress of proxy.

Further analysis with the whole population will focus on influence of symptom burden, EoL-preparation, demographics, cancer types and spiritual needs on the QODD, on the association of other QI on the QODD.

**Discussion:** QODD seems to be an important outcome in PC. The results will provide the basis for implementation of tailored interventions of PC procedures by oncologists and other hcp, to improve the quality of life, death and dying in cancer pts.

## Spirituality

Abstract number: P1-361  
Abstract type: Poster

### Conceptualization of Suffering in Cancer - A Systematic Literature Review

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Relief of suffering is integral to palliative care, but the topic beyond physical suffering is not well understood.

A systematic review focusing on suffering across all cancers was undertaken. The aims were to:

- (1) Identify and synthesise conceptualisations of suffering;
- (2) identify surrogate terms for suffering;
- (3) identify antecedents of suffering; and
- (4) describe the consequences of suffering.

The search included peer-reviewed English articles focusing on the conceptualisation of suffering in adult cancer patients published between 1992 and 2012 in MEDLINE, Embase, PsycINFO, and the Cochrane Library databases. Seminal theoretical articles conceptualising suffering more generally were also eligible. To ensure identification of a broad range of conceptualisations of suffering in cancer, the search strategy was drafted iteratively. Study findings were subjected to conceptual analysis using the evolutionary method. 128 studies were identified which discussed definitions of suffering. Historical influences such as the writings of Victor Frankl, Cicely Saunders and Eric Cassell permeate the literature. Suffering was described as an all-encompassing, dynamic, individual phenomenon characterised by the experience of alienation, helplessness, hopelessness and meaninglessness in the sufferer which is difficult for them to articulate. It is multi-dimensional and usually incorporates an undesirable, negative quality. Many surrogate terms were identified. Antecedents and consequences of spiritual suffering are described. This review revealed that suffering includes spiritual suffering which is complex and difficult for patients to express. Those suffering need to be given opportunity to express their suffering and the potential for suffering to be transcended needs to be recognised and facilitated. Further effort is needed to educate healthcare workers in their understanding of this phenomenon.  
This project received funding from Cancer Australia.

Abstract number: P1-362  
Abstract type: Poster

### Meaning in Life and Spirituality at the End of Life

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**Background:** Meaning in Life (MIL) is recognised as one of the most affected domains in a significant number of patients with terminal illness and has been included as a possible modulator of quality of life in several studies.

**Aims:** The aims were to identify the areas relevant for the patients' meaning in life and to assess the relationship between desire for hastened death, anxiety/depression and meaning in life, spirituality, and religiosity.

**Method:** MIL (assessed by the Schedule for Meaning in Life), spiritual wellbeing (Functional Assessment of Chronic Illness Therapy), religiosity (Idler Index of Religiosity), anxiety/depression (Hospital Anxiety and Depression Scale) and desire for hastened death (Schedule of Attitudes towards Hastened Death) were assessed with face-to-face interviews in the three linguistic regions of Switzerland (French, German and Italian regions, FR, GR and IR).

**Results:** Up to now, 77 FR, 83 GR and 27 IR patients have been interviewed. Significant differences between regions regarding the areas contributing to MIL were observed: 'religion/spirituality' is rarely cited by the IR patients compared to FR and GR (3% vs 23% vs 51%, respectively,  $p=.000$ ). 'Work' is more often cited by IR patients compared to FR and GR (63% vs 9% vs 26%, respectively,  $p=.000$ ). Both MIL and spiritual wellbeing are negatively correlated with anxiety/depression ( $R^2=.1011$ ,  $p=.002$ ;  $R^2=.303$ ,  $p=.000$ , respectively) and desire for hastened death ( $R^2=.066$ ,  $p=.037$ ;  $R^2=.090$ ,  $p=.012$ , respectively), with a difference between FR and GR patients (stronger negative relationship in FR patients).

**Discussion:** Differences have been observed between the three regions, which may relate in part to the different understanding of the concepts of spirituality, religiosity, and meaning in life. Before developing a specific meaning-enhancing intervention, we need to better understand how the different populations interpret these concepts and relate them to each other.

Abstract number: P1-363  
Abstract type: Poster

### Challenges in the Practice of Palliative Sedation in the Islamic World: A Case Based Reflective Report

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**Aim:** PS in Islam is not well described in literature. This report describes the ethical dilemma and challenges in palliative sedation (PS) among Muslim patients in Saudi Arabia.

**Case1:** 56 year male with terminal cancer and lung metastases with significant dyspnea and pain, requested to be 'put to sleep for most of the day'. He wanted to be unaware of his pain and dyspnea especially during nursing. He believed it is Islamic to request PS as it exempts prayer for the dying. His caregiver didn't approve of PS; concern was that he will be unable to pray.

**Case 2:** 14 year boy with sarcoma and lung metastases with dyspnea in the last hours of life. His father agreed to PS but the boy refused. He wished to be able to perform prayers before death.

**Islamic perspective:** Prayer is one of the pillars of Islam that must be performed five times a day. However, a sick person is allowed to pray sitting or lying down. A very sick person may be excused from not being able to pray. While it is a rule in Islam that any Muslim should be allowed the maximum time to perform the religious rite of prayers, Islam also allows the prohibited in the face of hardship. Based on this principle many medical interventions, including PS are permissible in Islam.

The counter argument to PS is that suffering at EOL doesn't merit being unable to pray.

PS does not intend to hasten death unlike euthanasia. Islam judges an action based more on the intentions (Niyah) than on the consequences.

The counter argument is that PS may hasten death and this is prohibited.

Physician responses: The attending physicians were Muslims; felt PS for symptom relief is Islamic. The decision of the patient is final.

**Conclusions:** PS is acceptable to Muslim patients and physicians. The PC team should be aware of these principles while caring for Muslims and document patients' opinion regarding PS at EOL.

Abstract number: P1-364  
Abstract type: Poster

### Performance Status and its Association with Quality of Life and Spiritual Wellbeing

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**Background:** Life limiting illnesses can lead to poor performance status (PS), which may have an adverse effect on one's quality of life (QOL). Previous studies have shown that PS is related to QOL, but the relationship between PS and spiritual wellbeing is less studied. This abstract reports the association of PS with QOL and spiritual wellbeing, which are both important components in palliative care.

**Aim:** We hypothesise that better PS is associated with better QOL and higher spiritual wellbeing in palliative care patients.

**Method:** As part of a larger study looking at the effect of a spirituality programme on QOL and spiritual well-being of palliative care patients referred to a consultative inpatient palliative care service and a hospice homecare service from March to September 2014, the associations of PS with QOL and spiritual wellbeing were analysed. FACT-G, a 27-item questionnaire, was used to measure QOL in physical, social, emotional and functional domains, and SP 12, a 12 item tool, was used to assess spiritual wellbeing. PS was measured using ECOG where scores of 0-2 indicates good PS and scores of 3-4 indicates poor PS. Analysis were done using unpaired T test.

**Result:** Out of 144 patients, 97 had good PS, and 47 had poor PS. There was a significant difference in QOL between patients with better PS (73.13±18.19) and patients with poor PS (62.78±16.90),  $t=3.26$ ,  $p<0.001$ . When comparing spirituality wellbeing with ECOG status, there was no statistical significance,  $t=1.70$ ,  $p=0.091$ . However, patients with good PS (33.20±10.31) had a slightly higher spirituality score compared to patients with poor PS (30.04±10.25).

**Conclusion:** QOL is an important outcome of care at the end of life. This study showed that PS was associated with QOL, but not with spiritual wellbeing. This may mean that a patient could have poor PS but still maintain spiritual wellbeing and vice versa. Further studies could be done to assess the effect of deteriorating PS on spiritual wellbeing.

Abstract number: P1-365  
Abstract type: Poster

### Raising the Bar: Demonstrating Improved Spiritual Awareness in a Critical Mass of the Healthcare Workforce

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**Background:** A Systematic Literature Review of Spiritual Care (Holloway 2011) undertaken for the End of Life Care Strategy in England highlighted the need for education of frontline staff.

**Aim:** To assess whether a programme designed to raise awareness, increased the confidence, skills, knowledge and ability to recognise, and address, the spiritual and religious needs of patients.

**Method:** Two Cancer Networks in the North of England commissioned an experiential awareness raising package consisting of both e-learning and face to face taught components. Facilitators were trained to deliver the face to face (F2F) component locally in a cascade fashion and the e-learning (online) programme was managed and facilitated centrally. Each participant completed a pre and post course questionnaire based on a Spiritual Care Competency Framework (Gordon and Mitchell 2004). The results were analysed together and separately for each mode of learning.

**Results:** Since 2007, 1939 participants have undertaken the course: 1722 F2F; 217 online.



Participants were nurses, doctors, social workers, healthcare assistants and other health and social care workers. For this evaluation pre and post course questionnaires were completed by 646 participants: 421 F2F and 215 online. Overall there were statistically significant differences in questionnaire scores obtained for knowledge about understanding and meaning of spirituality, skills in discussing spiritual issues and distress, and confidence in assessment and documentation, apart from issues of confidentiality and the ability to build relationships with patients and families which were not significantly different. There were only slight differences between the scores for F2F and online learning.

**Conclusion:** The course provides demonstrable increased awareness of spiritual issues, patient needs and how to address them, with participants expressing increased confidence, skills and knowledge unrelated to the mode of learning despite this being an experiential course.

**Abstract number:** P1-366  
**Abstract type:** Poster

## Spinal Spirituality: Audit of the Documentation of Spiritual and Religious Needs Assessment and Care in a Regional Spinal Injuries Unit

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**Background:** The importance of spiritual and religious care is highlighted repeatedly in the NICE Supportive and Palliative Care Guidance 2004, End of Life Strategy 2008, NICE End of Life Quality Standards 2011 and One Chance to get it Right 2014. Regional audits of the documentation of spiritual and religious needs assessment and provision of care by those involved in specialist palliative care services have resulted in a widespread education programme open to all across healthcare settings. Following attendance on such a programme and as part of an End of Life Skillset Challenge, it was agreed to audit this on the regional spinal injuries unit, where end of life care is infrequently undertaken but many of the goals of care are re-adaptive following significant trauma causing lifestyle change.

**Method:** Retrospective review of 20 sets of hospital clinical nursing records looking for evidence of documentation of spiritual and religious needs assessment and provision of care using an audit tool created as part of the Opening the Spiritual Gate Programme across the local Palliative and End of Life Network.

**Results:** 95% clinical nursing records had documentation of the patient's faith tradition or religious affiliation, however none mentioned the importance, or otherwise, of this to the patient. None had any record of spiritual or religious needs assessment and only 10% had any record of ongoing spiritual care.

**Recommendation:** As a result of this audit, and at the same time as a Spiritual Care Policy happened to be published for the hospital, a Spiritual Care Plan was written by the auditor and agreed for use. A simple awareness raising programme was undertaken within the unit before repeating the audit. This presentation will include the results of the second cycle and demonstrate the impact of the intervention.

**Abstract number:** P1-367  
**Abstract type:** Poster

## Religious Beliefs towards the End of Life among Patients with Chronic Heart Failure and the Relationship with End-of-Life Preferences

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**Background:** Religious beliefs may influence decision-making about end-of-life care among patients with Chronic Heart Failure (CHF) and may change towards the end-of-life. Data in CHF are scarce.

**Aims** of this longitudinal observational study were: to explore whether preferences for life-sustaining treatments and end-of-life care are influenced by religious beliefs among patients with CHF; and to explore whether religious beliefs change towards the end-of-life.

**Methods:** This study included 427 patients with CHF of the TIME-CHF study (69% of the original sample; 62% male; mean age 76.6 (7.5) years; 62% NYHA class III). Confession, strength of religious beliefs (Religion Questionnaire), preferences for CPR, and willingness to trade survival time for excellent health were assessed (Time Trade-Off tool). The relationship between religious beliefs and preferences for CPR and willingness to trade survival time at baseline was explored. In addition, changes in religious beliefs between baseline and 12 months were explored among patients who died between 12 and 18 months.

**Results:** 47% were Catholic, 42% Protestant, 5% other and 6% atheist. Atheist patients more often preferred 'Do Not Resuscitate' (DNR) than Catholic patients (56% vs 32%, respectively,  $p=0.03$ ). Patients with strong religious beliefs as assessed with the Religion Questionnaire were less likely to prefer DNR than patients without religious beliefs ( $p<0.05$ ). There was no relationship with willingness to trade survival time ( $p>0.05$ ). The belief in afterlife increased among patients who died between 12 and 18 months ( $p=0.04$ ), while feeling supported by religion tended to decrease at the end of life ( $p=0.07$ ).

**Conclusions:** CHF Patients with strong religious beliefs are less likely to prefer DNR. Religious beliefs may change towards the end-of-life. Therefore, exploring religious beliefs and the influence on preferences for life-sustaining treatments as part of advance care planning seems to be important.

**Abstract number:** P1-368  
**Abstract type:** Poster

## Mis-use of Spiritual Care as Set-back in Drug Adherence in Patient with Chronic Illnesses: Case Observation from a HIV Positive Child in Tanzania

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**Aim:** A follow-up case study of a child LM 16 years old that has been on care and treatment since birth (acquired from parents).

**Design, methods and approach taken:** HIV infection is a chronic lifelong disease. The person infected might be using ARV's or not depending on the level of the immune status (CD4 cell counts) and clinical features. Poor adherence to treatment causes the suppression of the immune status and gives a room for opportunistic infection to affect different part of the body. Any infection that reaches the central nervous system may lead to mental health problems. Spirituality is the quality or state of being concerned with religion or religious matters: the quality or state of being spiritual.

The child LM was asked to stop taking antiretroviral drugs and start eating pieces of paper with written religious verses with a belief of getting rid of the virus from his body afterwards. The child stopped attending care and treatment clinic. Follow-up plan was arranged to trace the child, unfortunately the home address was changed. The child made self-referral back to the clinic after 6 months while in a poor condition and he was alone.

**Results:** it was found that, the child had stopped medication for more than six month. He had multiple opportunistic infections with CD4 dropped from 764 cell counts to 26 cell counts in six (6) month period. Family centered care were employed where by all family members, religious leader (sheikh) and other health care discipline were involved. Drugs re-adherence counseling sessions was conducted and ARV drugs were re-initiated.

**Conclusion / lessons learned:** Spiritual care plays vital roles in improving the quality of life of a sick person but should be used with care lest lead to delay in seeking of health care services. Lack of comprehensive care where spirituality is part of care is the key barriers. There is still a weak link between spiritual care and other care in order to create a holistic care in Tanzania.

**Abstract number:** P1-369  
**Abstract type:** Poster

## Impact of Religiosity and Spirituality on Health Information Preferences at the End of Life

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**Background:** Copious research studies have linked spirituality and religiosity to psychological well-being among cancer patients at the end of life. Furthermore, spirituality and religiosity have been shown to shape patients' views and preferences at the end of life (True et al., 2005). However, little is known about the impact of religiosity and spirituality on health information preferences in this population.

**Aims:** We aim to examine the impact of religiosity and spirituality on health information preferences, in addition to investigating the contributing roles of anxiety and depression.

**Methods:** 117 patients from a larger RCT of meaning-centered psychotherapy with non-localised or recurrent cancer completed the self-report measures capturing demographic information, religiosity, spirituality, health information preferences [Health Information Preferences (HIP)], and anxiety and depression [Hospital Anxiety and Depression Scale (HADS)]. Analysis of variance (ANOVA) compared scores for HIP among participants.

**Results:** Preliminary results indicate that patients identified as 'very much' religious preferred to receive significantly more health information from their medical team, than those identified as 'not at all' religious ( $p<.05$ ). No significant differences in HIP scores were identified between patients who reported varying degrees of spirituality. Furthermore, age and HADS scores were not significantly correlated to HIP scores. Additional analyses will explore medical, demographic, and clinical variables that might help predict health information preferences.

**Discussion:** These results support the notion that religiosity does impact a patient's preferences at the end of life. Furthermore, religiosity independently predicts a patient's preference for comprehensive health information regardless of anxiety and depressive symptoms. We contribute to the current literature and provide evidence a unique benefit that religiosity holds at the end of life.

**Abstract number:** P1-370  
**Abstract type:** Poster

## Reflections on Faith among the Dying in a Secularised Society - A Qualitative Study about Faith among Patients Admitted in Danish Hospices

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**Background:** Studies suggest spiritual care support may help patients at the end of life cope with their imminent death and improve their quality of life. Denmark is known for secularism with low levels of religious belief and practice when Danes are compared with other nations. Thus it is problematic to transfer insights gained from research in more religious societies about spirituality into a Danish context. There is a knowledge gap about the significance and character of spirituality among Danish dying patients; therefore it is difficult to develop and implement targeted spiritual support.

**Aim:** To illuminate how Danish patients admitted to hospice reflect on their faith in the last stages of life.

**Method:** Data were generated through ethnographic fieldwork comprising 17 semi-structured interviews with dying patients and 38 days of participant observation at three hospices.

**Results:** Five themes were combined into three categories. The category 'knowing' reflected that patients expressed a cognitively weak conceptual framework for faith although they believed in something transcendent and in afterlife. Their faith was influenced by Christianity but in varying ways. The category 'doing' demonstrated how patients lived out their spiritual praxis where most were embedded in hesitant and uncertain manners. The category 'being' exposed several patients with intensified focus on their vague articulated faith. Faith could be imbued with deep feelings such as peace and less loneliness in some, and anger, sorrow and loneliness in others as they coped with their imminent death.

**Conclusion:** In this study Danish patients at the end of life had a hesitant but important faith



construct when coping with death. It is crucial to support patients regardless of their religious coping strategies or struggles. Yet, how to support patients in praxis is complex and perhaps even more difficult than in more religious societies because of these patients' weak cognitive framework for faith.

**Abstract number:** P1-371  
**Abstract type:** Poster

## Boon or Bane? Staff Perception on the Use of FICA and FACIT-Sp Spirituality Tools

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**Background:** Although spirituality is an integral part of palliative care, it is often under-addressed. The FICA Spiritual History Tool was developed to aid healthcare staff in spirituality assessment, while the Functional Assessment of Chronic Illness Therapy-Spiritual (FACIT-Sp) Well-being Scale was developed to measure spiritual wellbeing in patients.

**Aim:** This study aims to evaluate the perceived usefulness and burden of using FICA and FACIT-Sp.

**Methods:** As part of a larger study on spirituality in a tertiary hospital palliative care consult service and a hospice home care service, half of the palliative care staff were trained to use FICA to take a spiritual history and all staff used FACIT-Sp to measure spiritual wellbeing. A survey was administered to palliative care staff at both sites 3 months after the start of the study.

**Results:** Overall, 40 staff responded. Fifty five percent found FACIT-Sp useful, 7.5% did not, 20% were not sure and 17.5% did not respond. Of the 22 who found it useful, 68.2% found it useful for opening up conversations with patients and 68.2% for exploring spiritual issues. When asked if they found it a burden, 37.5% said no, 32.5% said yes, 12.5% were not sure and 17.5% did not respond. Many of those who found FACIT-Sp a burden felt it was too time-consuming, especially for fatigued patients.

All 16 who had used FICA and gave feedback found it useful - 75% found it useful for exploring spiritual issues, 69% for opening up conversations with patients, 50% for building rapport and 50% for identifying spiritual problems. Four found FICA burdensome because it was time-consuming and patients got fatigued easily. However, when asked if they would recommend its use to others, 81.2% said yes.

**Conclusion:** This study showed that FICA and FACIT-Sp can be helpful in opening up conversations with patients and exploring spiritual issues. However, they can also be time-consuming especially for patients who were fatigued.

**Abstract number:** P1-372  
**Abstract type:** Poster

## "I am Still from outside Even though I'm Part of the Team" - Self-Perceived Roles of Clinical Pastoral Carer Workers within Palliative Care

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**Background:** To accompany seriously ill and dying has always been an inherent part of pastoral care. Nowadays, clinical pastoral care workers are specially trained for delivering spiritual care in the context of dying and death. But since the consolidation of palliative care (PC) and its interdisciplinary approach to spiritual care, it becomes difficult to define the specific profile and essence of clinical pastoral care.

**Aim:** To analyse: the perspective of Protestant clinical pastoral care workers on their diverse roles in delivering palliative care within the clinical setting.

**Methods:** 29 qualitative, semi-structured expert interviews with clinical pastoral care workers in southern Germany were conducted in 2013. The interviews were transcribed verbatim and a qualitative content analysis was performed.

**Results:** In addition to providing general pastoral care by supporting patients, families and team members through counselling, conversations and rituals, participants also described the following roles: being a fellow human being, a PC team member, a mediator between families, patients and the team, and an advocate for unheard or unregarded issues.

Moreover, autonomy and openness seemed to be central motives in the work of clinical pastoral care workers and were characterised by the self-directed organisation of schedules, an individual and open approach to pastoral care for each recipient, and the addressing of challenging topics within the team and with patients.

**Conclusions:** Clinical pastoral care encompasses various roles that go beyond traditional counselling. As employees of the church, pastoral care workers come from 'outside' into the clinical setting but are still part of the PC team. This enables them to question routines and 'normalities' in a constructive way, to act as intermediary and to offer space and time to patients, families and the team in an otherwise often structured clinical routine.

**Abstract number:** P1-373  
**Abstract type:** Poster

## Audit of the Facilitation of Spiritual Care for Patients by Clinical Staff at the EllenorLions Hospice, UK

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**Background:** Since the foundation of the modern hospice movement, spiritual care has been regarded as a vital part of patient care, alongside physical, psychological and social considerations. This holistic approach to Palliative Care is upheld by and reflected in the NICE Guidance on Supportive and Palliative Care (2004) and the DOH End of Life Strategy (2008). One of the Quality Markers for Spiritual Support in End of Life Care proposed as part of the 2008 EOL Strategy was: 'People approaching the end of life... have the opportunity to explore their spiritual beliefs and values with staff at regular points throughout the illness trajectory and these are recorded and regularly reviewed.'

**Objectives and standards:** To assess whether some of the essential, basic elements of assessing and facilitating spiritual care for patients, were part of the standard practice of clinical teams at the Hospice. The following criteria were selected: Record of religious

affiliation, Exploration of spiritual needs (either conducted or considered), Consideration given to potential chaplaincy involvement.

**Methods:** 45 patients electronic records reviewed in total -15 each from inpatients- (IPU), Home care (HCT) and Day therapy (DTU).

**Results:** The recording of religious affiliation was more consistent on IPU (93%) than either the DTU or HCT (both 73%). Performance in each of the 3 categories considered by this audit fell short of the set-targets: Religious was recorded in 80% of cases compared to the goal of 95%. Spiritual Care Needs were assessed or considered in 41.5% of patient assessments compared to the target of 80%. Chaplaincy Referral was offered or thought of in 20% of instances, against the aim of 67%.

**Discussion:** Reflection on the demographic mix of the audit population and the potential effect on results suggest a number of interesting questions for future research regarding factors that might affect the assessment of spiritual care needs. We plan to reaudit further to this.

**Abstract number:** P1-374  
**Abstract type:** Poster

## Effect of Standard Palliative Care on Spirituality Wellbeing and Quality of Life in Patients over Time

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**Background:** Palliative care (PC) is an approach that improves the quality of life (QOL) of patients and their families, by addressing physical, psychosocial and spiritual issues. Spiritual care is important in the care of patients with life-limiting illnesses. However, the impact of standard PC on spiritual wellbeing in patients over time is not well-documented.

**Aim:** We postulate that standard PC is associated with improved spiritual wellbeing and QOL in patients over time.

**Methods:** This analysis forms part of a larger study, which uses FACIT-Sp to evaluate the effect of a spirituality program on spirituality wellbeing and QOL of patients receiving PC in an acute hospital and at home. FACIT-Sp is a validated instrument consisting of the 27-item FACT-G scale measuring QOL and the 12-item Sp-12 scale measuring spiritual wellbeing. Measurements were done within first 5 visits by the PC team, and subsequently 3 visits after. Higher scores signify better spiritual wellbeing/QOL.

**Results:** Patients who received standard PC were included (N=51), including hospice homecare patients (n=37) and hospitalised patients referred to a PC service (n=14). For homecare patients, measurements occurred between an average of 42 days (SD=20.2; 4±3.7 visits), compared to an average of 10 days (SD=10.1; 4±1.6 visits) in hospitalised patients. Using 2-tailed paired t-test, no significant differences were seen in spiritual wellbeing in patients between PC visits, whether at home (m=34.1±9.7 at 1<sup>st</sup> vs. m=32.9±10.7 at 2<sup>nd</sup> measurement, p=0.26), or in hospital (m=31.3±10.7 at 1<sup>st</sup> vs. m=35.0±9.0 at 2<sup>nd</sup> measurement, p=0.05). There were also no significant differences in QOL scores.

**Conclusion:** Spiritual wellbeing and QOL did not improve at an average of 4 PC visits, whether at home or in hospital. However, in view of the small study sample and absence of a control group for comparison, it is unclear if PC impacts spiritual wellbeing and QOL scores. Further large comparison studies are required.

**Abstract number:** P1-375  
**Abstract type:** Poster

## Research on Integration of Chaplains in Palliative Consultation Teams, a Methodological Challenge

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**Background:** The IKNL, the main Dutch organisation in the field of palliative care has decided to focus mainly on medical and nursing subjects. The WHO-definition of palliative care also mentions spiritual aspects to be part of good and integrated palliative care. The IKNL has divided the country in regions with consultation teams with specialised doctors and nurses who give advices to general practitioners, med. specialists and nurses.

Integrating chaplains in these teams probably is a good method to get more awareness for the existential and spiritual needs. The consultation teams could be working more in line with the WHO-definition by giving advice on how to care for this needs as well. Research on this subject till now on has not been done in the Netherlands and not in other countries either.

**Aims:** The aim is to find a way to do research on the value of integrating chaplains in palliative consultation teams.

**Methods:**

- Research in literature about chaplains taking part in consultation teams
- Drawing outlines for the analysis of the (effect of) spiritual background/life of members of consultation teams: do they have a well defined spiritual background and/or active spiritual life and what is the effect of that on their work as palliative consultant?
- Drawing outlines for the analysis of regional differences between consultation teams in urban areas in the western part of the country and those working in the Bible Belt, with a more orthodox religious population
- Drawing outlines for the measurement of attention for spiritual care in consultation.

**Results:**

Comparison between 4 teams:

- a. team in Amsterdam area with at least one chaplain
- b. team in Amsterdam area without a chaplain
- c. team in the Bible Belt with at least one chaplain
- d. team in the Bible Belt without a chaplain.

**Conclusion:** It is possible to do demonstrate the value of membership of chaplains in palliative consultation teams in respect to integrated palliative care as meant in the WHO-definition. This research has been developed with Prof. C. Leget and was discussed with dr. G. Handzo, who was very interested and willing to help in the ongoing process of researching. Leget offered to give advice in the further development of the research.

**Abstract number:** P1-376

**Abstract type:** Poster

## Does Pain and Spirituality Have an Effect on Quality of Life?

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**Background:** In the past, several studies have shown positive impact of spirituality on Quality of life (QOL) in oncology patients, with fewer studies showing similar correlation between symptoms and QOL. There is little data exploring the relationship between pain, spirituality and QOL in palliative care patients.

**Aim:** We postulate that patients with better spiritual well-being will have better QOL despite being in pain.

**Method:** Baseline data was obtained from a larger intervention study looking at the effect of a spirituality programme on QOL and other outcomes. The Functional Assessment of Chronic Illness Therapy—Spiritual Well Being (FACIT-Sp) was used to measure QOL and spiritual well-being. Patients who were referred to palliative care completed the FACIT-Sp and pain assessment in one sitting within their first five visits from time of referral to a tertiary hospital in-patient palliative care service or an outpatient home care service. The spirituality scores were divided into two groups, whereby patients with scores above the median were assumed to have better spiritual well-being. Scores recorded for pain, spiritual well-being and FACT-G were later analysed using two-way ANOVA.

**Results:** Out of 134 patients, pain ( $p < 0.005$ ) and spirituality ( $p < 0.005$ ) were independent factors affecting QOL. Even though there was no statistical significant interaction between pain and spirituality on QOL,  $F(2,128)=1.471$ ,  $p=0.233$ , our results showed that patients with pain and better spiritual well-being ( $73.61 \pm 14.02$ ) had higher mean QOL score compared to patients with pain and lower spiritual well-being ( $56.78 \pm 13.61$ ).

**Conclusion:** Pain and spirituality were found to be independently associated with QOL. Our results further implied that better spiritual well-being may result in better QOL despite pain, even though there was no statistical significance. Further studies will be required to look into other symptoms and its relationship with QOL and spiritual well-being.

## Social care and social work

**Abstract number:** P1-377

**Abstract type:** Poster

## Analysis on Causes of Hospital Death Despite the Preference for Home Death: Cases of Liver Cancer Patients Home-cared at End-stage

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**Aims:** Although over half of Japanese prefer home death and home care is more prevalent today, only 8% of cancer patients die at home. While the long-term treatment of liver cancer gives time for home care preparation, home death is considered difficult due to various symptoms including sudden deterioration. We analysed the factors affecting the place of death of home cared liver cancer patients.

**Methods:** We studied 67 cases of end-stage liver cancer patients for whom we coordinated the place of end-of-life care from April 2012 to November 2013 and analysed the factors of discontinuation of home care.

**Results:** Among 67 patients, 5 died at our hospital while coordinating, 47 were referred to home care physicians, and 15 were under care. Out of 52 who died, 27 died at home. We obtained details of 24 patients preferred home death from home care staff, of which 14 died at home and 5 at hospital; 1 patient was admitted as recommended by the home care physician, and the rest 4 were the results of the families calling ambulance being worried after seeing hepatic encephalopathy or hemorrhage. Among patients over 70 years old, 1 out of 5 died at hospital and 10 out of 14 at home. The families of home deaths received more details of physical conditions. Home deaths were realised by larger families, and those realised required more care, implying that hardness of home care does not lessen the home death cases.

**Conclusion:** Although most liver cancer patients preferring home care and death were home-cared, some died at hospital. The results suggest that providing detailed information on clinical course and possible sudden changes in physical condition is important, and continuous communication between the families and the hospital after starting the home care will be possibly helpful. In addition, certain number of families calling ambulance upon sudden change of patients' conditions might be inevitable, thus it is advisable that hospitals are fully prepared for palliative emergency.

**Abstract number:** P1-378

**Abstract type:** Poster

## Problems with Palliative Care Systems for Advanced Cancer Patients in Large Metropolitan Areas

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**Background:** Many patients undergo outpatient anti-cancer treatments in Tokyo. However, when cancer advances and patients can no longer make hospital visits, no systems are in place to connect them with community hospice or home care services. This study examines the community partnership of patients who received care from our palliative care team, as well as its systems for providing palliative care within its coverage area.

**Method:** We studied medical records of advanced cancer patients who received interventions by the palliative care team between January 1 and December 31, 2013, including performance status (PS), outcomes, and the location of end-of-life treatment. We studied the problems of partnership in large cities based on the results of a survey on

partnership related to palliative care that targeted 739 facilities, including hospitals, home care clinics, visiting nurse stations, and home care support providers within the coverage area. The chi-square test was used for statistical analysis.

**Results:** Of 346 patients, 10% were transferred to hospice care within the area, 20% were transferred to hospice care outside of the area, and 38% died in the hospital. The number of patients with PS3 scores who were transferred to home care or hospice care in their own communities was significantly higher than those with other PS scores. Efforts to form collaborative partnerships have been impeded by lack of information on patient conditions and patient anxiety about how to deal with worsening symptoms. Home care support providers have a lot of information about their communities, but it is difficult to obtain information about individual patients.

**Conclusions:** This study suggests that building effective partnerships must happen not just between hospitals, but in collaboration with businesses like care service providers that have not traditionally been included in such partnerships. Also, decision-making support must be provided while patients still have good PS.

**Abstract number:** P1-379

**Abstract type:** Poster

## Social Care Intervention for Cancer Patients in the Adult Outpatient Clinic

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**Introduction:** Our palliative care outpatient clinic for adults is staffed on a daily basis with doctor and nurse and access to social worker, psychologist consultation pharmacy services, etc as required. The social worker has the task to step into an existing doctor patient relationship and to form also quickly a trustful relationship with the patient and the family by offering support for getting access to various benefits.

**Aim:** To determine the social worker's interventions implemented in the care plan of adults patients in the outpatient clinic.

**Method:** A quantitative, retrospective study has been conducted between January 1st to September 30, 2013. All patients that required diverse social care interventions were included in the study and data were collected from their files.

**Results:** 100 patients were identified in the reviewed period. Out of them 51 were women and 49 men;

66 from urban area and 34 from rural area, main age group was 51 to 60 years and was represented by 40 patients. Interventions performed were assessment of social needs and counseling for all 100 patients, support for obtaining handicap certificate and disability pension 100 %, information and facilitation in obtaining new location of address in the ID card for 33 persons (for patients coming at end of life from other regions of the country in order to benefit from free medical care they have to have a local address), identifying financial resources for 62 beneficiaries and their family.

**Conclusion:** Social worker's interventions in the outpatient clinic for adults are challenging. Good knowledge and understanding of specific legislation, the existing social network available locally for underserved communities is crucial.

**Abstract number:** P1-380

**Abstract type:** Poster

## The Role of the Social Worker in the Adults' Day Care Center

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**Background:** Our organisation offers palliative care services in several settings: home care, ambulatory, inpatient unit, day center, hospital teams, urban and rural area. In the day center we care for cancer patients with good performance status (ECOG 1 and 2). Our services are free of charge and offered by a multidisciplinary team. There is a part time social worker attached to the day care team to evaluate the patients' social needs and offer interventions.

**Goal:** To understand the role and work of the social worker in the day centre.

**Method:** Retrospective study reviewing interventions of the SW conducted in the day centre between September 1<sup>st</sup>, 2013 and September 30<sup>th</sup>, 2014. patients' charts and social worker's reports were analysed creating an excel database.

**Results:** In the period of time studied, all 92 patients (100%) enrolled in day care have benefited by the interventions of the social worker: 50 patients (54%) received - on a monthly basis, social support (food package, clothes), for 60 patients (65%) the social worker has obtained or renewed the handicap certificate (a certificate giving some financial benefits to holders), 21 patients (23%) benefited from or have had renewed the medical pension. Other interventions of the social worker consisted in 429 visits to local public authorities (social departments, town hall, legal offices) and 1112 social counseling sessions with an average of 12 sessions per patient.

**Conclusion:** The social worker is the spokesperson of the patient negotiates on behalf of the patient, in order to access social benefits, have legal rights respected and ensure and offers direct care especially counseling for problems like social isolation, anxiety, financial support for the patient.

**Abstract number:** P1-381

**Abstract type:** Poster

## Palliative Care Social Work Roles and Tasks Vital for Patients and their Families

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**Background:** EAPC white paper on core competencies for palliative care social work will be published in November 2014. It has highlighted the need to clarify what specialist palliative care social workers and to strengthen and preserve their role. In the UK the College of Social Work has published the professional capabilities framework and work has begun to link concepts and ideas from the two publications.

**Aims:** A questionnaire has been pilot tested using the current members of the EAPC social work task force and their national associations. The revised questionnaire is being translated and will be sent out in January 2015 The results will be analysed and published later in 2015.

However this presentation will examine the results of the pilot project and our discussions with colleagues in Europe.

**Conclusions:** The questionnaire and results showed a wide variation in tasks, the overlapping of roles with counsellors, psychologists and allied health professionals but also the increasing need for the legal-socio aspects of the role particularly in relation to safeguarding vulnerable children and adults, the assessment of capacity and deprivation of liberties and complex discharges to a variety of care settings. Professional social workers have the skills which require the capacity to work within the competing needs of the patient, the family and the agency

The demographic changes across the whole of Europe will also increase the need for this part of the role as extending palliative care to non cancer conditions particularly dementia becomes more of the norm.

## Psychology and Psychiatry

**Abstract number:** P1-382  
**Abstract type:** Poster

### 'Worried to Death': The Assessment and Management of Anxiety in Patients with Advanced Life-limiting Disease, a National Survey of Palliative Medicine Physicians

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**Background:** Anxiety is common in palliative care patients and adversely affects quality of life. However, there is little evidence regarding drug treatments and no UK-wide or international guidelines on the assessment and management of anxiety in this population.

**Aim:** To undertake a UK national survey to explore how palliative care physicians assess and manage anxiety in their patients, and to identify any barriers they may encounter. In doing so, it aims to provide information to guide service development and research.

**Method:** An online questionnaire was sent to all doctors working in adult specialist palliative care in the UK who were members of the Association for Palliative Medicine (total 980). Responses were analysed using descriptive statistics.

**Results:** The response rate was 23% (230/980) and 61% of respondents were consultants. Most did not use tools to screen for anxiety (87%) and used the clinical interview to diagnose anxiety (99%). Only 19% used psychiatric criteria or a diagnostic tool. Most doctors reported difficulties managing anxiety (25% frequently, 68% sometimes). Only 33% felt they had adequate training in this area and 66% did not have direct access to psychological or psychiatric services. The majority used a combination of drug and non-drug treatments. The most frequently prescribed medications for patients with a short prognosis were benzodiazepines (87%), particularly lorazepam. For patients with a longer prognosis, antidepressants were most frequently prescribed (51%).

**Conclusion:** Despite the low response rate, this is the first UK-wide survey of palliative care physicians. It suggests that most physicians are not using standardised, validated methods to assess anxiety and that there is substantial variation in practice, particularly drug treatment for patients with a longer prognosis. It highlights gaps in training, access to psychological and psychiatric services and identifies the need for research to develop evidence-based guidance.

**Abstract number:** P1-383  
**Abstract type:** Poster

### The Effect of Health Care Settings and Health Care Conditions upon Hopelessness and Loneliness Levels

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**Background and objectives:** It is a reality that work life affects individuals and individuals affect work life. Health sector is different from other sectors in the sense that it serves sick individuals who undergo intense stress and health care workers often face stressful events on the daily basis. Health care workers -especially nurses- may be psychologically affected by work setting and the job itself. Working under stress for a long time may affect workers' psycho-social states; which may lead to loss of positive attitudes towards patients, themselves and life and as a result negative feelings may emerge. Negative feelings like loneliness and hopelessness may play an etiological role in the occurrence of physical and psychological problems. The study was planned to explore loneliness and hopelessness levels of the nurses working at intensive care units, psychiatry units and surgery units.

**Methods:** The study was conducted at three different hospitals in Istanbul. 82 nurses working at intensive care units, psychiatry units and surgery units were included in the study. Nurses were administered a questionnaire form and UCLA loneliness and hopelessness scale.

**Results:** 28% of the nurses worked at psychiatry units, 32.9% at surgery units and 39% at intensive care units. It was found out that male nurses had higher levels of loneliness and hopelessness than female nurses. Loneliness and hopelessness levels of those nurses who worked for ≥ 9 years at the same unit were higher. In terms of clinics where nurses worked; intensive care nurses had higher hopelessness levels while surgery nurses had higher loneliness levels. Psychiatry nurses had lower loneliness and hopelessness levels.

**Conclusions:** We were of the opinion that work setting and work conditions affected nurses' loneliness and hopelessness levels and recommended that work conditions of intensive care units and surgery units should be improved.

**Abstract number:** P1-384  
**Abstract type:** Poster

### End of Life Process as Observed by those who Faced Death Most

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**Background and objectives:** Those working in health profession are always in a position to see death and a dying person. Health care workers who do not recognise the patients' situations and their own emotions feel despair and may not professionally help the patients and their families. The emotions created by the health care workers may negatively affect their provision of effective treatment and help. The study was planned to assess the end of life process as observed by the intensive care team members who faced death most at hospitals.

**Methods:** A total of 80 personnel made up by doctors and nurses working at four different intensive care units of Istanbul Medipol University were included in the study. The data were gathered using a questionnaire of 19 questions.

**Results:** Most of the participant personnel emphasised that they faced death before, felt sorry and cried in first death case, felt hopelessness while providing care to a patient in the end of life process and finally comforted themselves by accepting that death is a natural process. Most of the health care personnel believed that diagnosis should be told to a patient who is in the terminal phase and patient should spend the terminal phase at their homes. Health care personnel would like to know the life expectancy if they were a terminal patient. As for CPR intervention to the terminal patient; it was seen that half of the participants told that it should be done while other half told that it should not be done.

**Conclusions:** We were of the opinion that it is important that health care workers be aware of their own ideas about end of life process and death and that they be empowered to effectively cope with the negative emotions.

**Abstract number:** P1-385  
**Abstract type:** Poster

### Depression and Religious/Spiritual Coping in Palliative Care Ambulatory Patients: Are there any Relations? - A Brazilian Sample

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Depressive symptoms are common in Palliative Care (PC) patients, and religious/spiritual coping (RCOPE) could be used to deal with the psychological suffering. In Brazil, few studies has investigated the impact of RCOPE on psychological aspects, especially in PC settings. **Aim:** investigate RCOPE and depressive symptoms association in patients under Ambulatory PC in Medical School of Botucatu, State University of São Paulo.

**Methods:** cross-sectional study on a convenient sample of Ambulatory PC patients. Besides socio-demographic data, the relation between depressive symptom, RCOPE and other explanatory variables were investigated. Hospital Anxiety and Depression Scale (HAD), BriefRCOPE, Activities of Daily Life Scale (ADLS) and Karnofsky's Functional Scale (KFS) were used. Linear Regression models were built to multivariate analysis, including significant variables obtained on univariate analysis ( $p \leq 0.05$ ) and those appointed as risk factor in literature review.

**Results:** Forty people (30-85 years-old; mean: 68.5±12.8; women: 65.0%; Caucasian: 65.0%; married: 52.5%; living with partner: 57.5%; Cancer diagnosis: 40.0%) constituted the sample. On KFS the mean score was 72.75±16.8 and 65.0% were independent on activities of daily life (ADL). Depressive symptoms were present in 40.0% (CI95% 24.1-55.9%). The mean score of positive and negative RCOPE were 3.62±0.27 and 1.38±0.58, respectively. Multivariate analysis has revealed an association between depressive symptoms and 'major use of negative coping' ( $p=0.004$ ).

**Discussion / Conclusion:** an association between depressive symptoms and more use of negative RCOPE strategies has agreed with other studies findings. So, a religious/spiritual approach as care tool probably has a positive impact on quality of life and in reducing depressive symptoms in PC patients. More studies are necessary to evaluate the relations between religiosity/spirituality and health care, and how these relations could be used to benefit those under PC.

**Abstract number:** P1-386  
**Abstract type:** Poster

### Predictors for Psychological Burden in Palliative Care Patients - An Analysis of the Hospice and Palliative Care Evaluation 2007 - 2011

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**Background:** Psychological burden is common in patients with advanced or terminal diseases. This study aims to detect possible predictors for different aspects of psychological burden in palliative care patients.

**Methods:** We retrospectively analysed data of palliative care patients collected by the German quality management benchmarking system called Hospice and Palliative Care Evaluation (HOPE) which includes an evaluated symptom and problem checklist. We dichotomised staff's ratings for depression, anxiety, tension, and disorientation/confusion considering groups with none or mild (grade 0 and 1) rated symptoms versus moderate and severe (grade 2 and 3) rated symptoms. For each of these target variables we developed a multivariate logistic regression model by backward stepwise selection whose predictive accuracy was evaluated by the area under the receiver operating characteristic curve (AUC). As candidate predictor variables other information collected with HOPE were used.

**Results:** The analysis of 10444 data sets results in fair and good predictive values: depression (AUC=0.75), anxiety (AUC=0.74), tension (AUC=0.74), disorientation/confusion (AUC=0.82). In all of these multivariate predictive models burden of family/environment appears as one of the most predictive variable (AUC=0.65-0.69). The predictive models for depression,



anxiety and tension include more physical symptoms as the model for disorientation/confusion. While fatigue results as a predictor in all multivariate analysis (depression (AUC=0.63), anxiety (AUC=0.63), tension (AUC=0.63), disorientation/confusion (AUC=0.66)) dyspnea only appears as a predictor in the models for anxiety (AUC=0.64) and tension (AUC=0.62).

**Conclusions:** Predictive models for depression, anxiety, tension and disorientation/ confusion in palliative care patients were found and could be useful for clinical practice. Further analysis and research are recommended.

**Abstract number:** P1-387

**Abstract type:** Poster

## Dying Care and Spiritual Support Interventions in End-of-Life Care in Intensive Care Units Patients

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**Background:** About 17% patients are dying in the Intensive care units (ICU) in Czech Republic (CR). End-of-life care (EOLC) should be focused on not only biological symptoms but also on spiritual suffering, patient dignity and support the family's efforts. Dying Care and Spiritual Support interventions should be used for patients at the end of life.

**Aims:** The authors studied a usage of Dying Care and Spiritual Support interventions in EOLC in ICU patients in the CR and found the affecting factors.

**Methods:** The cross-sectional study with ad hoc questionnaire with Likert's scales and activities of Dying care and Spiritual support interventions was performed. The set composed of 277 nurses (mean age 38.5 years; mean practice 9.2±6.8 years). Mann-Whitney U-tests and Pearson correlation were used for statistics.

**Results:** The most and the less frequent activities were Treating the patient with dignity (mean 1.28±0.77) and Giving the patient expressed willingness to discuss death (mean 3.01±1.21). The significantly negative correlations were detected between the length of hospitalisation and activities in psychological ( $r=-0.209$ ,  $p=0.001$ ), social ( $r=-.207$ ,  $p<0.001$ ) and spiritual ( $r=-0.218$ ,  $p<0.001$ ) dimensions. Contrary, activities in psychological, social and spiritual dimensions positively correlated with personal conditions ( $r=0.216$ ,  $r=0.301$ ,  $r=0.330$ ;  $p<0.001$ ), nurse time options ( $r=0.158$ ,  $r=0.301$ ,  $r=0.312$ ;  $p<0.001$ ) and education about EOLC ( $r=0.271$ ,  $r=0.209$ ,  $r=0.270$ ;  $p<0.001$ ). The regard of nurses to death, frequency of care for the dying patients, the difficulty of communication with the dying patients and their families did not affect the frequency of activities in studied dimensions.

**Conclusion/ discussion:** Nurses in ICUs give the priority to the dignity of the patient's perception in EOLC in the CR. Further research should focus on factors that affect the EOLC in preserving the dignity of dying patients. Supported by grant FZV\_2014\_007.

**Abstract number:** P1-388

**Abstract type:** Poster

## Distress in Terminall Ill Patients at Home - Measurement of Psychosocial Burden in Community Palliative Care

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**Background:** Although most patients with advanced disease prefer to live at home, little is known about the psychosocial distress in such a setting. Untreated distress can lead to unnecessary suffering, more pain and fatigue, higher health service utilisation, reduced cognitive function and coping capabilities.

The aim of this study was to report the prevalence of psychological distress among palliative home care patients.

**Methods:** Between Sep 2013 and Sep 2014 all patients attended by an out-patient palliative care service in Germany were included in a prospective study. The Distress Thermometer (DT; 0-10) was applied to evaluate distress at the first encounter.

**Results:** 76 patients [mean age = 67 (SD =11); 57% female; 71% married; 91% in oncological condition; Karnofsky index 0-40=32%, 50-70=62%, 70-100=6%] participated. The incidence of distress (DT≥4) was 90% [mean=6.4 (SD=2.19)].

No statistical correlation was found between the level of distress and socio-demographic (age, gender, married or living alone) or medical factors (oncological/non oncological condition, Karnofsky index).

The 10 most reported problems were physical and emotional issues: fatigue (88%), getting around (82%), eating (62%), bathing/dressing (61%), sadness (61%), pain (58%), breathing (55%), constipation (54%), loss of interest in usual activities (53%), and worry (50%). The most frequently mentioned practical problem was getting around/mobility (17%); in the family category it was family health issues (25%); 5% of patients expressed spiritual/religious concerns. The number of problems reported correlated with the level of distress ( $r=0.5$ ).

**Conclusion:** A significant proportion of palliative care patients at home are severely distressed. The most frequent problems were of physical and emotional origin. The findings of this study highlight the importance of creating new concepts and structures to address the psychosocial needs of patients in palliative care at home.

**Abstract number:** P1-389

**Abstract type:** Poster

## Which Cancer Patients React to the Disease with Negative Emotions? Role of Demographic Factors and Type of Cancer

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**Background:** Although hearing diagnosis of cancer often involves negative feelings, not every patient reacts in the same way. While the level of negative emotions like anxiety and depression remains in some patients high, in others it is relatively low.

**Aim of the study:** The aim of the study was to assess the level of negative emotions (anxiety, depression) in patients with cancer, taking into consideration demographic variable and type of disease.

**Material and methods:** The study included 348 women and 224 men (19-91 years, M=54) with a diagnosis of cancer in one of the body areas: tissue and bones, gynecology, urology, lungs, breast, lymphomas, digestive system, head and neck. The group also included patients undergoing rehabilitation. Anxiety and depression were measured using the Modified Hospital Anxiety and Depression Scale (HADS-M). Demographic characteristics were measured using the Questionnaire on Demographic Variables.

**Results:** The results show that the highest level of anxiety and depression was observed in patients suffering from breast and gynecologic cancer; the lowest level in patients suffering from: urological, lymphomas and digestive system cancer. Women reported higher levels of anxiety and depression than men. We did not observe significant differences in anxiety and depression with regard to patients' education level or home town size.

**Conclusions:** The results indicate that there are certain group of patients that should be carefully observed, because of potentially worse adaptation to disease. These patients may need more often additional support and/or psychological interventions to lower their negative emotions and help them adapting better to the disease.

**Funding:** The study was funded with Institute's research budget.

**Abstract number:** P1-390

**Abstract type:** Poster

## Psyche at the End of Life: Psychiatric Symptoms in Patients Admitted to a Palliative Care Unit

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**Background:** Underdiagnosis of psychiatric symptoms is an essential issue in patients suffering from cancer and is paid even less attention in palliative treatment.

**Aim:** To evaluate the frequency as well as the therapeutic implications of undetected psychiatric symptoms in patients on a palliative care unit (PCU).

**Methods:** Patients admitted to one of five participating PCUs were included. The short version of the Patient Health Questionnaire (PHQ-D) was used for diagnosing mental health. It consists of measures for depression, panic and psychosocial impairment. Pain intensity was rated on a numeric rating scale (NRS) from 0-10 by both patients and their attending physicians. The amount of pain medication and psychopharmacological medication was assessed. Opioid dosages were expressed as oral morphine equivalent (OME).

**Results:** Data of 68 patients, 66% female, 34% male, were available for further analysis. Undetected psychiatric symptoms were found in 38%. Preexisting psychiatric comorbidities were evident in 25%, who received significantly more often antidepressants and benzodiazepines than patients without psychiatric symptoms or patients with undetected psychiatric symptoms ( $p<0.001$ ). Significant correlation between patients' and physicians' median NRS on pain intensity was observed ( $p=0.001$ ). Median NRS showed no significant difference between patients without, preexisting or undetected psychiatric symptoms ( $p=0.111$ ). OME did not differ significantly between patients without, preexisting or undetected psychiatric symptoms ( $p=0.526$ ). Patients with undetected psychiatric symptoms as well as patients with preexisting psychiatric comorbidities presented with a significantly higher impairment in the activities of daily life than patients without psychiatric symptoms ( $p=0.003$ ).

**Conclusion:** Undetected psychiatric comorbidities are common in patients receiving palliative care and should be incorporated in order to optimise treatment and reduce psychosocial burden.



Abstract number: P1-391  
Abstract type: Poster

### Burnout Syndrome in Staff Working with Children with Incurable Diseases

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**Introduction:** Disease, suffering and death of a child's life contradicts human conception about life, potentially leading professionals who care for such children to burnout. Christine Maslach defines this concept as: 'a syndrome of physical and emotional exhaustion that includes the development of a negative self-esteem, a negative attitude towards work.'

**Aim:** Identification of elements of burnout syndrome in staff working with children with incurable illnesses

**Method:** Survey of pediatric staff using self-administered Maslach Burnout Inventory (MBI) questionnaire with 22 items on 3 domains: emotional exhaustion, depersonalisation, low level of personal achievements. 5 units were selected to include onco-pediatrics departments (OP), ICU, long term care(LTC) and pediatric palliative care (PPC) units.

**Results:** Out of the 170 professionals surveyed 129 valid questionnaires were returned (RR=75,8%). There was a balanced representation of various units: 22,18% OP departments, 25,11% ICU staff, 27,91 PPC units, 24,8% LTC. 98,45 respondents were women; 97% had a full time job; 55,04% nurses, 23,26% aid nurses, 11,63% doctors, 10,8 others. The largest group 30,2% were those with 5-10 years of work experience; for 98,4% believe in God was rated as very important, 82% being orthodox Christians. The domain most influenced was personal achievements: 83,75% high and moderate burn-out (nurses being the main group as profession 52,86%; PPC staff being the largest group 57,14% as service), followed by depersonalisation (75,97%- nurses main group 71,43%) and emotional exhaustion (39,54%- largest group nurses 55,56%). 73,64% don't recognise their need of specialised support especially senior staff ( $p < 0.05$ ), as well as people who are severely or moderately burnt out in the emotional exhaustion ( $p < 0.01$ ).

**Conclusions:** Even if the results in terms of Burnout Syndrome are not extremely worrying compared with results of studies in other countries, preventive measures are welcomed.

Abstract number: P1-392  
Abstract type: Poster

### What Do We Understand by the WTHD? Results from a European Nominal Group

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**Background:** Recently, the phenomenon of a wish to hasten death (WTHD) among patients with advanced disease has attracted growing interest. However, conceptualising the WTHD and establishing its scope is not an easy task, since the phenomenon appears to cover a range of situations and the terminology used in the scientific literature often lacks precision and consistency.

**Aims:** To further our understanding of the WTHD through a nominal group (NG) process involving European experts in the field.

**Methods:** Clinicians and researchers with experience in the area were recruited by intentional sampling to participate in a NG convened in Barcelona in November 2013. The NG was conducted according to a predetermined schedule involving four stages: generating ideas; structured and time-limited discussion; summary and conclusions; and prioritisation of the main conclusions reached.

**Results:** Seventeen professionals from 15 European institutions took part. It became apparent that there is lack of conceptual precision regarding the WTHD, thus underlining the need to develop a new operational definition. The consensus was:

- in order for the new definition to be useful it would need to be acceptable to a sufficiently heterogeneous group of professionals,
- the definition should be reserved for patients with a predominantly physical illness or condition,
- the wish to die being referred to should be linked to suffering that could have several different dimensions, and
- although the definition might be applicable to a wide range of patients its scope should be clearly set out so as to highlight those situations to which it would not apply, for example, a mere 'acceptance of death'.

The group also agreed that an international Delphi study would be an ideal way of reaching a definition that fulfilled each of these characteristics.

**Conclusion:** An agreed operational definition of the WTHD would allow better communication both within and between groups of researchers and clinicians.

Abstract number: P1-393  
Abstract type: Poster

### Photo Making in Hospice: Can the Process of Constructing Images Restore the Changed Self-image that Accompanies the Diagnosis of a Life-limiting Illness?

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**Background:** Photography and self-portraits have been used in healthcare, yet no study has documented the experiences of hospice patients' participation. Our hospice has recently started to offer patients the option to make self-portraits/portrait photographs.

**Aims:** To explore the lived experiences of day hospice patients participating in the self-directed photographic portraiture experience.

**Methods:** Audio-taped semi-structured interviews were conducted using a topic guide. Interviews were transcribed and analysed using narrative analysis. Seven respondents were interviewed: three patients, two hospice staff observers and two photographers. Fourteen interviews were conducted - each participant was interviewed before and after the photographic session.

**Results:** The following themes were identified during analysis:

The participants constructed photographs to represent who they are rather than focussing on their illness.

Participants chose not to reinforce the more negative elements of illness progression but rather to accept them.

Life-limiting illness, ageing and treatments damage the patient's sense of self. This may be experienced as a form of grief or loss.

**Conclusion/discussion:** Patients provided unique insights into the experiences of changes that come with life limiting illnesses, articulating losses that resulted. In all cases the patients felt a profound difference between the image they held of themselves and the photographs they created. Patients said they benefited from this methodology of reflective photographic self-portraiture. This study straddles both arts and healthcare. The results have helped shape this intervention for future patients.

Abstract number: P1-394  
Abstract type: Poster

### Profile of Quality of Life and the Interplay of Anxiety Disorders among Individuals with Breast Cancers in Nigeria

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**Background and aims:** Quality of life (QOL) is stimulatingly recognised as a useful measure of outcome in cancers. This study investigates the influence of anxiety disorders on QOL in cohorts with breast cancer in a developing context.

**Methods:** The study participants consisted of 200 consenting females with breast cancer. Designed questionnaire was used to elicit their socio-demographic and clinical profile.

European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) was administered to assess QOL across functioning and symptom domains. This was followed by interview with the anxiety subscale of Hospital Anxiety and Depression rating Scale (HADS) to ascertain presence of anxiety disorders.

**Results:** The mean age of participants was 49.6±11.2 years, 76.5% were married, and majority of them were employed (59.5%). In terms of clinical factors, the mean duration of illness was 8.46 months, Chemotherapy (50.0%) was the commonest mode of treatment and most of the subjects (97.5%) were compliant with treatment. More than half of them (54%) presented at the late stages (stage 3 and 4). Overall, more than a quarter of the participants (26.5%) had anxiety based on HADS score of 8 and above. Anxiety disorders correlated positively with lower mean scores on all the breast cancer QOL functional scale domains, however with higher mean scores on the symptom scale ( $p < 0.05$ ).

**Conclusions:** In this study, varied degrees of impairment in functioning and worse experience of symptoms were observed; with anxiety disorders constituting determinant of QOL. Multidisciplinary-based management of breast cancer having full complement of supportive care is implied.

**Abstract number:** P1-395

**Abstract type:** Poster

## The Impact of Group Cohesion on Clinical Outcomes in Advanced Cancer Psychotherapy Groups

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**Background:** Studies of group cohesion indicate its role as a predictor of positive outcomes and a proxy for therapeutic alliance in group psychotherapy interventions. Yet, there is limited research on the role of group cohesion and other process variables in therapy groups for advanced cancer patients.

**Aims:** The purpose of this study was to examine group cohesion as a predictor of clinical outcomes in advanced cancer psychotherapy groups.

**Methods:** Patients with advanced cancer (n = 125) participated in a randomised controlled clinical trial comparing 8 weeks of Meaning-Centered Group Psychotherapy (MCGP, n = 67) with Supportive Group Psychotherapy (SGP, n = 58). Pre- and post-intervention assessments included the Group Cohesion Scale (GCS) and measures of spiritual well-being (FACIT-Sp), quality of life (MQOL), posttraumatic growth (PTGI), and benefit finding (BFS). Using a series of linear regressions, group cohesion was analysed as a predictor of several post-intervention clinical outcomes, controlling for pre-intervention levels.

**Results:** Overall, group cohesion significantly predicted post-intervention spiritual well-being and benefit finding, as well as posttraumatic growth (new possibilities) and quality of life (existential). In MCGP, cohesion predicted post-intervention benefit finding, while SGP cohesion predicted post-intervention benefit finding, posttraumatic growth, and facets of quality of life (social and existential) and spiritual well-being (meaning and peace).

**Conclusion / Discussion:** Stronger cohesiveness in psychotherapy groups for advanced cancer appears to enhance the ability of patients to find benefit and recognise growth, as well as to enhance spirituality and connectedness. Group cohesion was an essential ingredient that facilitated these existential and spiritual gains, and was especially important when the explicit group focus was members providing mutual support.

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**Abstract type:** Poster

## Anxiety and Depression in Cancer Patients: A Survey about the Hospital Anxiety and Depression Scale

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**Introduction:** Oncological patients in the last stage of their lives typically suffer from a combination of depression and anxiety. Focusing on depression in the psycho-oncological care of these individuals, symptoms of anxiety are frequently overlooked.

**Aim:** The aim of this survey was collecting data on the combination of anxiety and depression in hospitalised oncological patients in a Central European tertiary care center using the validated Hospital Anxiety and Depression Scale (HADS).

**Method:** A total of 200 patients underwent the HADS questionnaires at the time of first contact. HADS scores were considered normal when < 7, borderline when 8-10, and abnormal when >11.

**Results:** Overall, 159 patients (79.5%; 71 women and 88 men, 80 ≥65 years of age and 79 < 65 years) returned completed questionnaires. HADS scores were < 7 in 34.6%, 8-10 in 19.5%, and ≥11 in 45.9% of the investigated patients. Abnormal HADS scores ≥11 were found in 47.1% of men and 46.9% of women (p = 0.580) and in 44.0% of those < 65 and in 50.0% of those ≥65 years of age (p = 0.463).

**Discussion:** Anxiety and depression as assessed by the HADS questionnaire is highly prevalent among oncological inpatients.

**Abstract number:** P1-397

**Abstract type:** Poster

## The Interrelationship of Death Anxiety and Coping Mechanisms with the Attitudes towards Hospice Palliative Care in Hungary and in English Speaking Countries

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**Background:** Although hospice care in Hungary is becoming well-known, in everyday practice there are numerous questions evolving around the fact what attitudes the population holds towards hospice care and what other dispositions are associated to it as well as how the taboo around death could be eliminated.

**Aim:** The aim of this research is threefold:

- 1) to introduce Wong's et al. (1994) death anxiety questionnaire in Hungarian;
- 2) to generate scales measuring the attitudes towards certain fields of hospice and end-of-life care;
- 3) to provide a comparative insight into the interrelationship of death anxiety and coping mechanisms with the attitudes towards hospice care on a Hungarian and an English speaking sample.

**Methods:** The participants of this study (N[HUN]=128; N[ENG]=25) filled in an anonymous online questionnaire that contained items related to death anxiety, coping mechanisms, hospice care, the importance of medical intervention in end-of-life care, oncological diseases, and knowledge about hospice care. Snowballing technique was applied for data collection. ANOVA, correlation and regression analyses were conducted.

**Results:** The results show that the Attitudes to Hospice Care Scale positively correlates with the Fear of Death Scale in both cases. However, the Hungarian sample shows less assertive coping techniques than the English speaking one. Besides, the former group shows significant correlation with Escape Acceptance and oncological illnesses.

**Discussion:** The findings show that in the Hungarian environment hospice care is associated with much more fear and negative emotions than in the first-world English speaking

environment. Death as the natural part of life is less accepted in the first group and active medical intervention in end-of-life care is viewed as a safer option. Coping with death and oncological illnesses tends to involve depressive thoughts and avoidance, whereas the English sample shows more acceptance towards death and less existential anxiety.

**Abstract number:** P1-398

**Abstract type:** Poster

## Increasing Clinical Anxiety over Cancer Patients' Dying Process Is Not Unavoidable, but Is Determinated by Disease Burden, Existential Concerns, and Social Support

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**Background:** Anxiety has not been as extensively studied in psycho-oncology research as depression but represents a unique problem in its own right. The course of changes in prevalence and predictors of anxiety disorders/clinical anxiety over cancer patients' dying process remains unclear.

**Aims:** To describe longitudinal changes in the prevalence and to identify determinants of clinical anxiety for terminally ill cancer patients over the dying process.

**Methods:** A convenience sample of 323 cancer patients was followed until death. Prevalence of clinical anxiety was identified as scoring ≥11 on the anxiety subscale of the Hospital Anxiety and Depression Scale. A multivariate logistic regression model with the generalised estimating equation was performed to examine longitudinal changes in and determinants of clinical anxiety.

**Results:** The proportions of cancer patients suffered from clinical anxiety (HADS-A scores ≥11) increased as death approached (17.20%, 21.65%, 26.39%, and 33.22% at >181, 91-180, 31-90, and 1-30 days before death, respectively). However, after controlling for other confounders, prevalence of clinical anxiety did not change significantly over the dying process. Except for metastatic status, clinical anxiety at end of life (EOL) was not associated with demographics and disease-related characteristics. Cancer patients suffered from more severe symptom distress, perceived high sense of burden to others, and reported strong social support were significantly more likely to experience clinical anxiety at EOL.

**Conclusion/discussion:** Time proximity to death *per se* is not a determinant of clinical anxiety nor is unchangeable demographics or disease-related characteristics. Adequate symptom management, lightening cancer patients' perceived sense of burden to others, and lifting the aftermath concerns and separation anxiety for those who are strongly connected with their social network are keys for decreasing the likelihood of clinical anxiety at EOL.

**Abstract number:** P1-399

**Abstract type:** Poster

## Anxiety Management Group Therapy, a 12-year Experience

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**Background:** Anxiety is one of the most frequent symptoms reported by cancer patients, with a major impact on quality of life. An anxiety management group therapy, designed into a 5-session format, was developed for cancer patients of all stages.

**Objective:** To describe and explore the efficacy of the anxiety management group therapy.

**Methods:** The group therapy consisted of 4 weekly sessions of 2 hours, with an additional session one month later. The Hospital Anxiety and Depression Scale (HADS) was completed before (T0), after the intervention (T1), and after a 1 month followed up period (T2). A numerical scale from 0 to 10 was used to measure the perception of control over their anxiety (0=no control; 10=complete control), and for quality of life and physical exercise (0=very poor; 7=excellent).

**Results:** From 2002 to 2014, a total of 334 patients participated in the group, with an average age of 55 years, including 82.1% of women, and a drop-out rate/loss-to-follow-up of 18%. A significant difference in the HADS global score was observed between before (T0) and after (T1) the intervention (18.6 Vs 13.8; p< 0.001), and both for the anxiety (11.4 Vs 8.6; p< 0.001) and depression subscales (7.2 Vs 5.2; p< 0.001). Statistical difference was obtained between T1 and T2 on the global scale (p=0.01) and anxiety subscale (p=0.01) but not the depression subscale (p=0.11). Participants significantly perceived they were more in control of their anxiety (from T0 to T1, scores from 4.5 to 6; p< 0.001), with even a more significant improvement at T2 (score of 6.6; p=0.01). Quality of life significantly improved between T0 and T1 (scores from 4.3 to 5; p< 0.001) and between T0 and T2 (4.3 to 5.1; p< 0.001). The physical activity improved significantly from T0 to T2 (4.3 to 5.0; p=0.01), but not from T0 to T1.

**Conclusions:** Participants greatly improved their quality of life, anxiety, and depression, and their physical activity after this pragmatic, inclusive group therapy.

## Research methodology

Abstract number: P1-400

Abstract type: Poster

### Utilising Data from Social Media in Palliative Care Research: Developing an Ethical Framework

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**Background:** Social media has altered the way we live, and in many ways the way that we die. Online communities are full of discussions about illness, death and dying and these communications are increasingly being repositioned within research environments as potential sources of publically available data. The Marie Curie Palliative Care Research Centre (MCPRC) has been keen to embrace social media within its work; however there is no definitive set of ethical or practical guidelines by which to work with this data. The centre thus initiated two consensus days, with staff members meeting with external researchers with expert knowledge in the field, to construct a workable, ethical framework for its future research in the field.

**Methods:** Seven researchers from within the centre and two external experts in online research focused on constructing a set of ethical guidelines. Issues of confidentiality, anonymity and informed consent were all discussed.

**Results:** The following points are considered to form the basis for ethical, online research: Consent should always be taken from participants for the use of their online communications as research data.

Recruitment of participants should be transparent with adequate opportunity for participants to ask questions.

Information sheets should be provided and be clear about confidentiality issues that are specific to online research.

Potential anonymity issues in dissemination of research must be highlighted to participants. Authenticity is not considered an issue of significance for the MCPRC.

The use of historical text is considered to be problematic and therefore not encouraged. Closed forums created specifically for research purposes are considered by the MCPRC to be the most appropriate way to conduct online research.

**Discussion:** The consensus days enabled the construction of a framework for good ethical practice in online research, which can now be followed as the centre develops this area of research.

Abstract number: P1-401

Abstract type: Poster

### Recruitment Issues in the Implementation of the Care Pathway for Primary Palliative Care (CPPPC)

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**Background:** The recruitment process for clinical studies is known to be time-consuming, this could be even more so for studies in palliative care (PC) research<sup>1</sup>. Also for this research project this proves to be true. Family Practitioners (FP) are asked to evaluate the use of the Care Pathway for Primary Palliative Care by filling web-based questionnaires and by asking some of their PC patients to do the same. Although 30 FP have been included yet, recruitment has consumed more time than expected in advance.

#### Aims:

- To describe barriers and facilitators for FP to start participating in a research project involving some of their PC patients.
- To evaluate the effectiveness of the strategies used to recruit FP and PC patients for this project.

**Methods:** Following the principles of action research, interviews with FPs having showed interest will be done. Conclusions of these interviews will be on both a practical level, to improve the recruitment process of this particular project, and on a theoretical level, to improve the generalisability of the findings for both primary care and palliative care research.

**Results:** So far, 25 FPs were included of 42 FPs reached by practice visits. This strategy has been more successful than continued medical education sessions (CME) : only 1 FP included of 41 FPs reached. Even FPs showing clear interest in the project had to be asked by the research team proactively whether they wanted to participate. More elaborated results will be available in May.

**Discussion:** Both primary care and palliative care research are research domains which are considered highly relevant for public health. It is important to find more effective ways to recruit participants in both these domains. Reporting the recruitment process of this project could help in this search.

**Reference:** 1. Le Blanc T, Lodato J, Currow D, Abernethy A. Overcoming recruitment challenges in palliative care clinical trials. JOP 2013 (9); 6: 277-282. doi: 10.1200/JOP.2013.000996

Abstract number: P1-402

Abstract type: Poster

### Study Limitation or Crucial Information? Understanding Missing Data in Palliative Care Research

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Studies conducted in palliative care often suffer from high rates of attrition largely due to disease progression. Yet, little attention has been devoted to the best way to handle missing data in palliative care research when attrition is high due to disease progression and death. The goal of this study was to provide an example of the treatment of missing data in palliative care research.

Data for this study were drawn from a larger cross-sectional study of decision-making capacity and neuropsychological functioning in terminally ill cancer patients. Participants were 58 terminally ill adults (ages 50-89) receiving inpatient palliative care and 50 healthy adults. Study participation included a one-hour interview involving a semi-structured interview, measures of neuropsychological and psychological functioning. Multiple imputation was used to estimate the values of missing data.

Only 36.3% of the terminally ill sample ( $n = 20$ ) provided complete data, notably 15.5% ( $n = 9$ ) expired before completing the study, and 15.5% ( $n = 9$ ) became too confused or ill to continue. Five imputed datasets were created using a linear regression model. The variables included in the imputation process included the reason for incomplete data, demographic variables, neuropsychological variables, and outcome variables. This resulted in a more complete and accurate dataset that allowed for the conduction of planned analyses. The high rates of attrition largely due to disease progression and resulting confusion, delirium, and death, led to a large amount of missing data. Multiple imputation analyses including the reason for missing data is a possible solution for better accounting for the experience of terminally ill patients. The issue of missing data in palliative care research warrants further discussion. Rather than viewing this as a weakness of the study, efforts must be made to appropriately treat missing data.

Funded by the National Institute of Health/National Cancer Institute.

Abstract number: P1-403

Abstract type: Poster

### Getting the Best Advice: A Systematic Appraisal of Delirium Clinical Practice Guidelines

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**Background:** The management of delirium in palliative care patients is often guided by expert opinion and extrapolated from other patient populations due to limited high level research evidence. Multiple delirium clinical practice guidelines (CPGs) have been written. However, the quality and validity of published delirium CPGs has not been reported.

**Aims:** To perform a formal appraisal of delirium CPGs (published from 2008 to 2013) using the Appraisal of Guideline research and Evaluation (AGREE II) instrument.

**Methods:** A librarian-assisted systematic search was conducted in multiple databases (Cochrane Library, Medline, Embase, CINAHL, PsychINFO, Scopus, TRIP) and complemented by a hand search of Google, Google Scholar and CPG organisation databases. Abstracts/full text and internet sources were reviewed by 2 researchers for inclusion. Available CPGs, retrieved from citations meeting agreed inclusion criteria, were first screened by 2 independent appraisers using the rigour domain of the AGREE II. CPGs with the highest rigour domain scores were then independently appraised by 4 appraisers using the full 23-item AGREE II tool. An overall rating for each CPG was given.

**Results:** The systematic search found 1629 citations and 29 website links. Seven of the initial 14 retrieved CPGs had rigour domain scores >40%. AGREE domain scores for the 7 CPGs ranged from 8 - 100%. Although the 2010 National Institute for Health and Clinical Excellence (NICE) CPG rated highly in all 6 quality domains, it specifically excludes 'people receiving end-of-life care'. Two CPGs, from CCSMH (Canadian Coalition for Seniors' Mental Health) and CCO (Cancer Care Ontario), had been developed for palliative care patients and were recommended for use with modification by the appraisers.

**Conclusion:** Utilising a formal appraisal tool highlights potential weaknesses in the CPG development process and ensures that only high quality delirium CPGs are adapted prior to implementation into clinical settings.

**Abstract number:** P1-404  
**Abstract type:** Poster

## Social Spaces and Singular Encounters: Challenges to Conducting Qualitative Research Interviews in Palliative and End of Life Care in the Home Setting

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**Aims:** Within palliative and end of life research, qualitative research interviews are often undertaken in the home. Despite practical and ethical challenges, little attention has been given in the literature to the impact of the home setting on managing a simultaneous research and social relationship with interviewees. This work looks to explore these issues and the implications for both participants and researchers.

**Methods:** The views and experiences of researchers from an academic palliative care research centre are presented. Eight experienced researchers from a range of backgrounds including nursing, occupational therapy, social science, psychology and palliative medicine, took part in a group consensus meeting to discuss their experiences of conducting qualitative research with vulnerable populations in the home. Further comment was included from a palliative medicine physician, also experienced in qualitative research.

**Results:** The researchers reflected on several important ethical and practical issues. These included ways in which to build rapport in often singular encounters, and applying sensitivity and flexibility in difficult circumstances. The research interview can become therapeutic for the participant, however interviewers need to be aware of unintentional power relationships between themselves and their participants and the implications for data quality, as well as both patients' and interviewers' physical and emotional safety.

**Conclusions:** In this setting, and with this particular patient group, less attention should be paid to interviewers' professional stance of neutrality and non-disclosure and more to allowing appropriate social contact, and humanity. However, care needs to be taken to avoid creating a false rapport and therapeutic environment that may cause ultimately distress to the participant as a singular encounter. Recommendations will be made to address both practical and ethical concerns for researchers working in this field.

**Abstract number:** P1-405  
**Abstract type:** Poster

## Following Not Missing the Thread

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**Background:** Within all studies there needs to be a recognised role for each individual method that adds independent value or depth to the study. However there is an additional requirement within a mixed methods study for data integration. There are three recognised approaches for achieving this; the use of the triangulation protocol; the use of a mixed methods matrix; and, 'following a thread'.

**Aim:** To identify what more can be known about the role of facilitation when implementing the Gold Standards Framework in Care Homes (GSFCH) programme within nursing care home practice when the findings from data generated by two or more methods are brought together.

**Methods:** Qualitative and quantitative data were collected from staff employed within (nursing care home managers and GSFCH coordinators) or associated with (external facilitators) 38 nursing care homes and included interviews, surveys, Facilitator Activity Logs and a researcher's diary. After separate quantitative (descriptive) and qualitative (thematic template) data analysis the data sets were integrated by 'following a thread'.

**Results:** 'Following a thread' resulted in the identification of a sub-theme in the qualitative data which had not been identified during the initial analysis of the quantitative data. The Facilitator Activity Logs were reviewed to see if there was any evidence of this sub-theme. Initial analysis of these logs had only taken account of the components of a specified high facilitation or the high facilitation and action learning facilitation role. The new sub-theme was not such a component. 'Following a thread' identified a significant association between the time a facilitator designated for accreditation and the nursing care home gaining accreditation ( $p < .01257$ ).

**Conclusion:** 'Following a thread' enabled epistemological triangulation. More became known about a phenomenon when the findings from data generated by two or more methods were brought together.

**Abstract number:** P1-406  
**Abstract type:** Poster

## Who Needs Need? A Qualitative Study of Need in People with Severe COPD

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**Background:** Healthcare need is a complex concept. Research suggests people with severe Chronic Obstructive Pulmonary Disease (COPD) have many unmet needs but are a 'silent' group.

**Aim:** To explore the concept of need in advanced COPD from patient/carer and professional perspectives.

**Method:** We recruited people with severe COPD from 2 hospitals in Scotland to complete action plans following discussion after discharge with a respiratory nurse with palliative care training. We analysed the plans and conducted a series of in-depth qualitative interviews with a subsample of patients and their family and professional carers. These were recorded, fully transcribed and entered into NVivo for thematic analysis using Bradshaw's classification of felt, expressed, normative and comparative need.

**Results:** 18 patients, 5 carers, 28 professionals provided 51 interviews, and 23 action plans. Some 'normative' needs were identified by professionals and some practical issues had been addressed during routine discharge planning. Other needs (physical symptoms and limitations, activities of daily living, social and financial concerns and existential issues) were 'felt' by patients and family carers but articulated in response to direct questioning by the researcher rather than actively 'expressed'. Patients often did not wish any action to address the problems, preferring care from family members rather than formal agencies. Many spoke of the over-arching importance of retaining a sense of independence and autonomy, considering themselves as ageing rather than ill. Few needs were identified by our intervention and few actions planned.

**Conclusion:** In contrast to professionally-defined 'normative' needs patients rarely perceived themselves as needy accepting their 'felt' needs as a disability to which they had adapted. Sensitive approaches that foster independence may enable patients to 'express' needs that are amenable to help without disturbing the adaptive equilibrium they have achieved.

**Abstract number:** P1-407  
**Abstract type:** Poster

## Building a Research Agenda Together: Involving Patients and other Stakeholders in Defining Research Priorities in Palliative Care

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**Background:** It is widely acknowledged that it is important to involve patients and other stakeholders in defining priorities in healthcare research. However, little experience exists in doing this in a systematic way.

**Aim:** To develop and test a method for involving patients and other stakeholders in setting priorities for research in palliative care, with a focus on social learning.

**Method:** Stakeholders were defined as those who are likely to experience the consequences of priorities in palliative care research in their daily life or work, and were enrolled through snowballing. Interpretive frames of stakeholders were reconstructed through interviews, revealing how background theories and normative preferences jointly determine stakeholders' problem definition and judgment of how research might help to resolve those problems. Based on the outcomes of these interviews, a systematic review of the pertinent literature was conducted. Findings of the review were presented to stakeholders for feedback.

**Results:** The key issues and concerns revolved around three main themes: (1) transition from a curative to a palliative approach, (2) meaning of life questions, and (3) continuity of care. Many of the questions came down to the question how research can help to develop and test strategies that can help patients and their relatives to discover the meaning of life in the presence of incurable disease. The results of the studies, retrieved through our systematic review, did not match well stakeholders' questions and concerns.

**Conclusion:** Developing and executing a research agenda that closely matches the questions and concerns of stakeholders remains a challenge. Reconstructing stakeholders' interpretative frames and sharing the results among them, may be a means of starting off a social learning process, resulting in more meaningful priorities for research. co-funded by the European Union (FP7-Health-2012-Innovation, grant agreement 30614)



**Abstract number:** P1-408  
**Abstract type:** Poster

## The Challenge of Gaining Access to Informal Caregivers in the Advanced Heart Failure Population in Ireland

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**Aim:** Explore the palliative care (PC) needs and quality of life (QoL) of patients with heart failure (HF) and their caregivers on the island of Ireland.

**Methods:** A sequential confirmatory mixed methods study consisting of a postal survey with patients and caregivers followed by a semi-structured interview with caregivers was undertaken. Databases within HF clinics in Northern Ireland and the Republic of Ireland were searched to identify advanced HF patients. Patients deemed physically and mentally suitable, ≥18 years, New York Heart Association Classification III-IV, ejection fraction < 40% and (i) brain natriuretic peptide > 400 pg/ml or (ii) ≥ 1 unscheduled hospital admission in the previous 12 months or (iii) on IV diuretics during the previous 12 months were invited to take part.

Access to the caregivers was via the patients. Data was collected on demographics, depression, anxiety, QoL, patients' perceived social support and illness beliefs, caregiver burden, needs assessment and preparedness for caregiving.

**Results:** The postal survey response rate was 50% and 36% for patients and caregivers respectively. Given that access to the caregivers was via the patients, caregiver's participation was mediated not only by the patient's gatekeepers but additionally by the patients themselves.

**Conclusions / lessons learned:** Advanced HF is a population who would benefit from PC services and it is widely accepted that caregivers play a vital role in facilitating the care and therefore the carer's experiences is a research priority. Albeit, undertaking research in this population of caregiver's is extremely challenging. Currently in Ireland, people caring for HF patients are not widely known to services and given the number of gatekeepers to caregivers, when recruiting via patients, gaining access to this population of carers is problematic. In order to adequately explore caregiver's experiences more innovative approaches are needed to recruit this group on to research studies.

**Abstract number:** P1-409  
**Abstract type:** Poster

## Identification of Knowledge Transfer and Exchange Frameworks for Palliative Care: Findings from a Scoping Review

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**Background:** Scoping reviews, despite being increasingly popular in health research, are still rarely used in palliative care research. Unlike systematic reviews, scoping reviews address broader questions, include studies with different designs and use different methods of quality appraisal. They are quicker to perform and enable inclusion of heterogeneous evidence, both necessary if examining knowledge transfer and exchange (KTE) models in palliative care. Although there are currently over 60 different models of KTE designed for various fields of health care, many of them remain largely unrefined and untested. Hence it is difficult to estimate their effectiveness in the context of palliative care.

**Aim:** The study aims to elicit appropriate KTE models for potential application in palliative care.

**Design:** A scoping review was designed according to the guidelines proposed by Arksey and O'Malley (2005) and Levac et al. (2010).

**Results:** Initially 7544 abstracts were identified as fitting search criteria. Following removal of duplicates 4865 remained for review by two researchers. Preliminary agreement on inclusion/exclusion was 78%, with approximately 10% of papers retained for full text review. Research was classified as 'seminal' (where a new model was proposed) or 'implementation' (where a specific model was appraised in practice). Commonly used models, including PARiHS and the OMRU, take account of the empirical evidence as well as the processes of putting the evidence into practice in particular settings.

**Discussion:** The scoping review has allowed us to identify studies outlining models of KTE in health care setting and will lead to analysis of their applicability to the complex demands of palliative care. Results from this review will identify effective ways of translating different types of knowledge to different palliative care providers and could be utilised in hospital, community and home care as well as future research.

**Abstract number:** P1-410  
**Abstract type:** Poster

## Mapping Social Support Systems in the Field of Specialized Home Pediatric Palliative Care (SHPPC)

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**Background:** Effectiveness of psychosocial support in families where a child suffers from a life limiting disease depends on the subjective perspectives of the actors involved. For the first time in pediatric palliative care (PPC) network maps(NMs) were used as a tool for the care givers to illustrate their perspective on their social support system.

**Aim:** The aim of study was to explore the applicability of NMs in SHPPC and to examine whether the use of NMs leads to a better understanding of how support networks influence coping in families with children in PPC.

**Method:** Study participants were close relatives who cared for a child at home that received SHPPC for at least 2 weeks. With a mixed method approach both quantitative and qualitative data were collected using NMs to identify and visualise all significant members of a participant's social network, the closeness and the quality of relations. The creation of the NMs was accompanied by deepening interviews. The data collection included the recording

of the interview, the NM itself as well as the automatic generation of structural data during the creation of the digital NM.

**Results:** Between 10/12 and 02/14 45 family caregivers were enrolled in the study. All participants of the heterogeneous sample were open to this method and took the time (mean 77 min) to visualise their support situation. Working with NMs was unanimously rated positive, even when hidden but burdening aspects were uncovered. Composition of support systems differed widely, even within the members of one family. For example, the numbers of named actors vary between 3 and 28 (mean 11), the number of actors perceived as negative between 0 and 18 (mean 1.9).

**Conclusion:** NMs are an appropriate tool for collection, reconstruction and assessment of the current support situation. Further studies should examine the usefulness of NMs for the understanding of the caregiver's support needs by the SHPPC team and for the development of intervention strategies.

## Volunteering

**Abstract number:** P1-411  
**Abstract type:** Poster

## Redesigning Volunteering and Building Community Engagement

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Integrating the former roles of Ward and Day Therapy Helpers and Receptionists, volunteer Hosts provide a positive, friendly greeting to visitors and support our aspiration of a 'building without barriers'.

The role aims to:

- Create a volunteer workforce aligned to the vision of the hospice
- Develop a flexible team able to respond to changing demands
- Provide peer support
- Provide hospitality and companionship to patients, relatives and visitors.

Inspired by the Help the Hospices Commission report 'Volunteers: vital to the future of Hospice care', and prompted by a new build, the Host role demonstrates an innovative approach to volunteering that supports our vision of creating a community that talks openly about dying. It offers volunteers a rewarding and life enhancing experience and has enabled them to more confidently respond to patients and their relatives and hold informed conversations with the public.

The new role demanded a 150% increase in volunteers and involved:

- Meeting with existing volunteers, explaining proposed changes and taking feedback
- Recruitment days and orientation prior to moving to the new hospice
- Providing guided tours to the public and in doing so enhancing building familiarisation.

**Outcomes:**

- Changes in the volunteer profile: 6% are under 30, and 19% male.
- New sections of our community have a greater understanding of hospices
- Engagement by a new generation of volunteers can help change societal attitudes.

A volunteer investment and value audit demonstrated a £7 return on investment for every £1 spent on volunteers. This role is informing plans for recruitment, induction and on going training for all volunteers and the flexible approach modelled is encouraging a change in organisation culture. The role and team approach to volunteering has potential to be replicated in other hospices and was well-received by senior hospice executives at a recent master class.

**Abstract number:** P1-412  
**Abstract type:** Poster

## 'The Asklepan Tradition?' Value of End of Life Volunteering According to Volunteers themselves

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**Background:** In the Netherlands each year more than 10,000 volunteers provide a contribution to palliative care at hospices and at home situations. The value of these contributions seems hard to frame from theoretical levels and is questioned from policy and professional care perspectives.

**Aim:** Therefore the aim is to explore the value of volunteering contributions to palliative care for clients, nearest relations, regular care and society. This study focuses on the question: what does volunteers' work bring to the volunteers themselves?

**Methods:** A call on the website of the Dutch national branch organisation VPTZ[1] resulted in more than 130 volunteers' letters; 100 of these were processed by a qualitative discourse analysis. Volunteers wrote on more themes than only the research question.

**Results:** The results describe motives to start as a volunteer and the character of their practice, and yield types and impact on the volunteers. A very clear result is the type of language that volunteers use to describe their experiences, it indicates a focus on 'being there' as a central concept. Furthermore, it strikes that volunteers' satisfaction relates to the quality of 'being there' in connection with a) making a difference, b) sharing experiences with other volunteers, and c) the environment in which volunteers function. Personal growth related to quality of 'being there' comes out as a prominent produce.

**Reflection and conclusion:** We reflect from an overview of different theoretical lenses on volunteers' contributions in end of life circumstances, with special attention to theories of presence, as well as to the so-called Asklepan tradition as described by Randall and Downie (2010).

The authors thank the KNR foundation (PIN Committee) for their support.

[1] Volunteers Palliative Terminal Care (The Netherlands)

**Abstract number:** P1-413

**Abstract type:** Poster

## Volunteering: What Does it Mean to Children's Hospices?

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In the UK today there are 50 children's hospices supported by approximately 17,000 volunteers, with an economic contribution of approximately £23 million. This paper reports on children's hospice data from a research study exploring the unique influence and impact of volunteers on UK hospices.

**Purpose of the research:** Using an innovative theoretical model of volunteering impact the purpose of the research was to:

§ Explore the influence of volunteers on key aspects of the service

§ Explore the differing perceptions of different groups on volunteering and its meaning to the hospice

**Method:** Because of the geographic spread, self-administered questionnaires were employed. Three online questionnaires were developed, one for each different participant group: trustees, senior staff and volunteers. These were sent to all independent hospices. Data were analysed by hospice type, hospice size, participant group and country, enabling a range of information to be extracted and compared.

**Findings:** Findings indicated that volunteers were vital to the ability of hospices to provide the level and range of services offered. They were considered to be an integral part of the staff team and were seen as important, not only to the care of children and young people, but also to supporting families. Their contribution was inextricably linked with the financial success of the organisation and they were perceived to have a key role in community engagement, public education and breaking down taboos around children's hospice care, helping to make it more accessible. A number of hospices indicated that they would have to close without the involvement of volunteers. There was a clear commitment to further developing their involvement in the care and support of children, young people and their families.

**Conclusions:** Volunteers are an essential part of children's hospices and their influence and impact is significant at all levels of the organisation.

**Abstract number:** P1-414

**Abstract type:** Poster

## The Role of the Volunteers and their Activities in Hospice and Palliative Care in Poland

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**Background:** In Poland volunteers are present in hospice and palliative care. They help patients and their families as well as they perform various services as non-patient facing volunteers.

**Aims:** The aim of the study was to examine volunteering in hospice and palliative care in Poland.

**Methods:** A cross sectional survey was applied. An anonymous questionnaire was addressed to hospice directors from Polish hospices which cooperated with volunteers. The respondents reported about the current state of volunteering at the unit they manage.

**Results:** 28 Polish hospices took part in this survey. 46% of the examined units cooperate with 10 to 30 volunteers and 29% of them with more than 30 up to 100 volunteers. The core volunteer roles are as follows: patients support (96%), patients' families support (68%), bereavement support (61%), and other, not associated with direct patient care (89%). The activities of volunteers are: organising patients' leisure time (75%), praying together (75%), accompanying patients (71%), feeding them (71%), cleaning their rooms (68%). Other activities include: organizing charity events and fundraising (68%), cleaning hospice building (54%), administrative and office work (32%). Hospice volunteers are obliged to: keep patient and family information confidential (89%), consult all activities connected with patients' care with hospice staff (86%), participate in a training (71%), know the patients' rights (61%). Improvement of patients' quality of life is a main benefit of volunteers' engagement in hospice and palliative care.

**Conclusion:** Volunteers value in the Polish hospice and palliative care in the perception of hospice directors is high. A key component of their role is the direct patient care and the improvement of patients' quality of life is the considerable advantage of their activity. Moreover, they also perform other services which are beneficial for the hospice.

**Abstract number:** P1-415

**Abstract type:** Poster

## Hospice Volunteers' Spiritual Care Training: Discussion on Core Competencies and Training Aims

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**Background:** A Germany-wide survey among the hospice coordinators confirmed that there is a need for assistance in arranging the spiritual care (SC) training. The survey highlighted the need for a SC curriculum designed for volunteers.

**Aim of the study:** This explorative study was designed to define the core competencies and training aims for the curriculum under construction.

**Methods:** Eight hospice coordinators were invited to participate in an expert group interview. The participants represented religious and secular institutions engaging various numbers of volunteers. All experts had a long-term experience of working in their institutions, but different experiences in teaching SC.

The interview lasted two hours. The audio recording was transcribed and analysed by two independent researchers using the thematic content analysis.

**Results:** The analysis revealed that SC training for volunteers should cover following themes and practical assignments:

(1) definition(s) of spirituality;

- (2) the role of different belief systems;
- (3) recognising spiritual needs and resources;
- (4) the meaning of rituals and creativity;
- (5) the art and ability to relate meaningfully,
- (6) initiating and ending spiritual encounters;
- (7) networking with pastoral care and community chaplains;
- (8) voicing and acknowledging own spirituality.

Two additional requests were proposed. Firstly, instead of lecturing practical exercises should be integrated in teaching spiritual care. Secondly, the educationalists should possess skills and experiences in pastoral care / theology and in hospice / palliative care.

**Conclusion:** SC is an essential part of the hospice volunteers' training. Hospice volunteers are confronted with a variety of spiritual needs in patients' and caregivers'. They are expected to identify spiritual distress and work with disrupted beliefs and value systems. The expert discussion highlighted that hospice volunteers need a proper end-of-life training that involves spirituality and SC.

**Abstract number:** P1-416

**Abstract type:** Poster

## National Hospice Volunteer Program Development in Hungary

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**Background:** According to a recent survey, volunteers are under-utilised in hospice care in Hungary. Only a few hospice care services train volunteers and these educational programs differ both in content and quality. The vast majority of hospice services are reluctant to train volunteers due to their limited knowledge and experience.

**Goals:** Development of a consensus-based national hospice volunteer training program and provide professional consultancy for hospice services to encourage and support them establishing local hospice volunteer programs.

**Methods:** During 2013-2014 two pilot hospice volunteer educational programs were held in Hungary: a forty-hours training (Pilot1) in Budapest by Hungarian Hospice-Palliative Association and a twenty-hours training (Pilot2) in Pecs by Pecs-Baranya Hospice Program. Pilots were compared and analysed in terms of content and efficiency.

**Results:** Nearly 80 candidates participated in the selection process. From these 33 people completed the training program in the two pilots. Approximately half of the trained volunteers support hospice teams actively. A multidisciplinary working group was established to evaluate the results. Analysing the content, Pilot1 more strongly prioritised on communication skills development while Pilot2 on field practice. The multidisciplinary group is working on the development of a consensus-based hospice volunteer training program (manuals and e-learning packages).

**Conclusions:** With the increasing demand for hospice care, services could benefit from volunteers' presence and support by widening the range of services provided, improving quality of care and reducing burdens of formal and informal caregivers. Development and dissemination of a consensus-based national hospice volunteer training program and its integration into the Hungarian Hospice-Palliative Care Guideline will contribute to achieve this purpose.

Supporter: EEA/Norwegian NGO Fund (Pecs-Baranya Hospice Program)

## Cancer

**Abstract number:** P1-417

**Abstract type:** Poster

## Patients' with Advanced and Terminal Cancer Reported Experience: The Importance of Nurses' Way of Caring

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**Background:** The nurse-patient relationship is key to provide individualised care and to improve the quality of life of the Person with Advanced and Terminal Cancer (PATC). Moreover, the relationship between the nurse and the person may influence in the global experience of the PATC.

**Aims:** To understand the nurse-PATC relationship and to identify its essential elements from patient's perspectives.

**Methods:** A qualitative study with a hermeneutic-phenomenological approach was designed. 16 PATC hospitalised at an oncology ward were interviewed in depth. They were asked to describe their relationship with oncology nurses.

**Results:** In the illness global experience of the PATC nurses play a decisive role. Patients when talking about the relationship with nurses refer to their way of caring considering the following aspects:

- (1) The way in which nurses take care of patients is an expression of their way of being.
  - (2) Patients feel nurses close through their words and actions.
  - (3) The affection and love of nurses is an essential element of the care.
  - (4) Patients are treated as persons despite their health condition and limited lifespan.
- As such they are cared in a holistic way considering their corporal and spiritual dimensions. PATC feel that the attitude of nurses and the way in which they care for them influences their hospitalisation period experience and in some cases even patients' life.

**Conclusion:** The way of being of nurses and their way of meeting the PATC is central when caring for them. Therefore professionals must be sensitive and conscious of the importance of the way in which they relate with these patients. It is essential to foster among nurses attitudes that lead to care patients as holistic persons with affection and closeness.

**Funding:** Plan Estatal I+D+i, ISCIII-Subdirección General de Evaluación y Fomento de la investigación, Project P13/O2313; and cofunded by Fondo Europeo de Desarrollo Regional FEDER, the European Regional Development Fund.

**Abstract number:** P1-418  
**Abstract type:** Poster

## Lung Cancer Diagnosed Following an Emergency Admission: Exploring Patient and Carer Perspectives on Delay in Seeking Help

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**Background:** Compared to others, patients diagnosed with lung cancer following an emergency, unplanned admission to hospital (DFEA) have more advanced disease and poorer prognosis. Little is known about DFEA patients' beliefs about cancer and its symptoms, or about their help seeking behaviours prior to admission.  
**Aim:** As part of a larger study we sought to gather patients' understandings of their symptoms and to discover what help, if any, they had tried to access prior to their emergency admission.  
**Methods:** A single centre, prospective mixed methods study conducted in one University hospital to compare the characteristics, needs, experiences and outcomes of lung cancer patients DFEA/not DFEA. We undertook qualitative interviews with patients DFEA and their carers. An aide memoire was developed to obtain patients' and carers' understanding of symptoms and experiences of trying to access health care services before admission to hospital. Interviews were recorded and transcribed. Framework analysis was employed.  
**Results:** 13 patients and 10 carers, plus 3 bereaved carers took part in interviews. 3 patient/carer dyads were interviewed together. Participants spoke about their symptoms and why they did not seek help sooner. They described complex and nuanced experiences. Some (n=12) had what they recalled as the wrong symptoms for lung cancer and attributed them either to a pre-existing condition or to ageing. In other cases (n=9) patients or carers realised with hindsight that their symptoms were signs of lung cancer, but at the time had made other attributions to account for them. In some cases (n=3) a sudden onset of symptoms was reported. Some GPs (n=6) were also reported to have made incorrect attributions about cause, such as sciatia, depression or tonsillitis.  
**Conclusion:** Late diagnosis meant that patients DFEA needed palliative support sooner after diagnosis than patients not DFEA. We suggest that a specialist palliative care assessment is routinely offered.

**Abstract number:** P1-419  
**Abstract type:** Poster

## Epidemiological Study and Prevalence of Palliative Patients in a Cancer Center of a French University Hospital

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**Background:** Impact of early palliative care for cancer patients on quality of life and overall survival has been recently demonstrated. Nevertheless the time of referral to palliative care support team (PCST) is still shortly before death. Indeed it remains difficult to identify palliative patients whose number varies depending upon the definition used.  
**Aims:** The primary end-point of this survey was to evaluate, in a cancer centre of a French university hospital, the prevalence of palliative patients according to the definition of the French Society of Palliative Care (SFAP) : i.e. with incurable, progressive and life-threatening disease. The secondary end-point was description of treatment protocols and clinical issues for each patient.  
**Methods:** We conducted a descriptive study on a given day on all inpatients using a standardised questionnaire, including 40 questions, reply from physicians of each department.  
**Results:** Out of the 85 patients hospitalised in the cancer centre (116% of bed occupancy), 19 patients (22%) were considered as palliative patients according to the SFAP definition. Patients' mean age was 63 years old (35 to 87). Solid tumors were the most frequently observed pathologies (74%), mainly gynaecologic malignancies. Scheduled treatment was the main motivation for hospitalisation (63%), followed by acute medical problem (32%). Most patients (95%) received specific treatment in the last month, to improve overall survival in 74% of them, according to the physicians. 85% of palliative patients were painful or uncomfortable and 37% were under the care of a PCST.  
**Conclusion:** Our work is the first French study revealing a high prevalence of palliative inpatients in a cancer centre. The treatments' stated aims (improving survival) should be questioned in the light of the high proportion of painful or uncomfortable patients. The low rate of partnership with PCST suggests difficulties to identify patients requiring a specialised intervention.

**Abstract number:** P1-420  
**Abstract type:** Poster

## Characteristics and Outcomes of Advanced Cancer Patients (AdCa) Evaluated by a Palliative Care Team (PC) at the Emergency Center (EC)

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**Background:** PC-EC partnerships are proposed as a way to increase earlier access to PC for AdCa. However there is limited research about clinical issues and outcomes of PC at the EC.  
**Methods:** A retrospective chart review of 200 consecutive AdCa referred to PC from the EC and 200 consecutive matched AdCa referred for PC from Inpatient hospital services(IPH), between 1/1/2010 and 12/31/2011. Demographics, frequency/intensity of ESAS-symptoms and PC interventions and outcomes were recorded.  
**Results:** Median age(Interquartile range=IQR); 56 years(48-67). 222(56%) were female. 243(61%)White and 78(20%)African American. No significant difference in age, race, and stage of cancer among two groups. Median time(IQR) from EC visit to PC was 12 hrs(7-23) v.

24 hrs(24-96) from IPH, p< 0.0001. The main reasons for EC visit v. IPH were uncontrolled pain[162(82%) v. 89(44%), p< 0.0001]; GI issues[82(41%) v. 38(19%), p< 0.0001], and dyspnea[58(29%) v. 38(19%), p=0.02]. The main median intensity(IQR) ESAS-symptoms in EC v. IPH were: pain[7(5-9) v. 5(2-8), p< 0.0001], fatigue[7(4-8) v. 6(4-8), p=0.0557], sleep[6(0-8) v. 4(1-7), p=0.08]. Other symptoms not significantly different. PC provided multiple not different interventions: opioid-management, medication review, bowel-regimen, antiemetics, and counseling. PC changed Do Not resuscitation status from 38(19%) to 89(45%, p< 0.0001). In the two groups, at follow-up ESAS-improvement(decrease ≥2 points)was: pain 125/238(53%), sleep 59/131(45%), Well-being 32/82(39%), fatigue 53/139(38%), anxiety 51/132(39%), appetite 46/132(35%), dyspnea 49/160(31%), nausea 52/170(31%) and depression 36/123(29%). After PC, 65(33%) AdCa in EC were discharged home with follow-up, 13(7%) home with hospice, 8(4%) inpatient hospice unit, 65(33%)admitted to regular floor, 46(23%) to palliative care unit.  
**Conclusion:** EC referral provided earlier access to PC. EC AdCa had more severe pain and 43% of AdCa EC were never admitted and could have missed PC-IPH.

**Abstract number:** P1-421  
**Abstract type:** Poster

## Experiences of Living with, and Undergoing Life-prolonging Treatment of, Metastatic Castration-resistant Prostate Cancer - A Qualitative Study

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Prostate cancer is the most common form of cancer amongst men in both Sweden and Europe. Once the disease has metastasised, and is no longer sensitive to hormonal (castration) therapy, it is considered incurable. However, since a few years back men at this stage of the disease have the opportunity to undergo different life-prolonging treatments. The knowledge about the effect of these treatments on different patient-reported outcome measures is very limited. Thus, the aim of this study was to, based on men's experiences of living with, and undergoing life-prolonging treatment of, metastatic castration-resistant prostate cancer (mCRPC), identify issues and matters of importance and significance to this group. The study also includes an evaluation of a questionnaire intended for use in a larger prospective research project including men in the corresponding situation. The study was conducted with qualitative design. Data was collected through nine interviews; five were semi structured and four were carried out with think-aloud methodology. The content of the interviews revolved around the questionnaire, as well as the participants' situation living with and undergoing treatment of mCRPC. Data was analysed using qualitative content analysis. In conclusion, the result indicates that living with and undergoing life-prolonging treatment of mCRPC could mean living in a world of uncertainty and change. This could be manifested in various ways, with physical, psychological, emotional, social and existential consequences. Information, knowledge and participation in decision-making appeared to be of importance. The complexity of these men's situations puts demands on health care, where a holistic view of the patient, continuity and trust were described as essential. The result was applied in the completion of the research project questionnaire.  
The study was carried out with financial support from Sophiahemmet research fundings and County council of Sörmland.

**Abstract number:** P1-422  
**Abstract type:** Poster

## Hypocalcaemia in Cancer Patients: An Exploratory Study

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**Background:** A 77 year old patient with bone metastases of prostate cancer was admitted in palliative care due to uncontrolled back pain. While at the palliative care unit he developed severe neuromuscular irritability. The ionised calcium was 0.55 mmol/L (1.17 - 1.38). IV Calcium gluconate was initiated with symptomatic improvement. However, the symptomatic control was not possible with oral calcium and the patient died in a few days.  
**Aim:** To explore the frequency of hypocalcaemia in cancer patients.  
**Methods:** Revision of the records of patients ≥ 18 years old, with a total calcium < 2.0 mmol/L measured in 2013.  
**Results:** 832 patients had a total calcium < 2.0 mmol/L. 441 (53%) were male. The median age was 63.5 years (18-93). The most frequent cancer diagnoses were hematological 197 (24%), colorectal 111 (13%), lung 86 (10%), thyroid 67 (8%), breast 54 (7%), stomach 51 (6%), gynecological 42 (5%) and prostate 38 (5%). 640 patients had a serum albumin measured, with a median of 25 g/L (14-47). When corrected for the albumin level, in 275 (33%) cases the calcium was in the normal range. The date of death was recorded in 283 cases to whom it was possible to correct the total calcium. Curiously, the median survival in the patients with corrected calcium lower than normal was 26.5 days (1-311) and that of patients with a normal corrected calcium was 19.0 days (1-395), p = 0.149, therefore non-significant.  
**Conclusion:** Hypocalcaemia in cancer patients may have many causes. It seems to be in general a sign of poor prognosis as the median survival was low, even for those with a normal corrected calcium, as this means that they have a low albumin, which is also a sign of poor prognosis. Independently of the survival impact, the symptoms due to hypocalcaemia may be important as in the clinical case presented, but that can be properly studied only in a prospective study.



**Abstract number:** P1-423

**Abstract type:** Poster

## Palliative Care in a Day Hospice Setting: The Experience of Policlinico San Matteo, Pavia

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**Introduction:** Early Palliative Care in recent years is becoming more widely taken into account. It's therefore emerging the need to develop organisational models aimed at an early integration of specific treatment and supportive care, to ensure a soft transition from active treatment to palliative care. We present our experience with advanced oncological patients in outpatient palliative care (OPC) setting.

**Methods:** A retrospective analysis of cases followed in the Day Hospital for Palliative Care between 01/01/2013 and 10/22/2014 was conducted. Data were extracted from medical records and the reports of the multi-professional team.

**Results:** 81 patients (pts), 46 males, mean age 72 years (range 43-91), were selected; main cancer diagnosis was metastatic gastro-intestinal in 24 and lung in 14. All patients were referred to our unit for uncontrolled symptoms, most commonly fatigue (69 pts), pain (54 pts), gastrointestinal disturbances (51 pts). All patients have received supportive intravenous therapies, including blood transfusions in 10, 7 pts required invasive procedures (paracentesis or thoracentesis). Thirty-two pts and their caregivers also received the support of our psycho-oncologist. The average time in which the patient was followed in OPC was 46 days (range 1-629). At data 10/22/2014: 7 patients were lost to follow-up, 17 pts are alive under treatment; 57 pts have died, the mean interval between the start of care and death being 60 days (range 1-212).

**Conclusion:** The transition between active treatment and palliative care can be a very critical stage in which feelings such as fear of abandonment, difficulty in adaptation and uncertainty for the future may emerge in both the patient and the family. Although in a limited sample, our experience of an early transition to an OPC setting appears favorable. Through a multiprofessional team it is possible to carry out proper treatment plan to ensure an easier transition between active and palliative care.

**Abstract number:** P1-424

**Abstract type:** Poster

## The Use of Transdermal Fentanyl in Patients with Cancer Cachexia - A Review of the Evidence

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**Background:** The transdermal route for administration of medication is felt to be preferable for some patients by avoiding the need for oral tablets or injections and aims to provide a constant rate of drug delivery. Fentanyl is a strong mu-opioid receptor agonist appropriate for transdermal administration because of high lipid solubility. It has been described that cancer-related cachexia can influence effectiveness of transdermal fentanyl patches.

**Aim:** To review the evidence for the use of transdermal fentanyl in patients with cancer cachexia.

**Methods:** Following the admission of a patient to a specialist palliative care unit who had developed cancer related cachexia and new inconsistent periods of opioid toxicity and withdrawal symptoms while using a fentanyl patch a review of the evidence for the use of transdermal fentanyl in patients with cachexia was undertaken. This was performed by searching Medline and NHS Scotland Knowledge Network (multiple databases including Embase and Cochrane) using the terms cancer, cachexia and fentanyl with subsequent hand search of references.

**Discussion:** Pharmacokinetics of fentanyl differ in patients with cachexia compared to normal weight. Review of literature suggests this is seemingly a result of structural and physiological skin changes, hypoalbuminaemia and altered metabolism. Low BMI alone does not seem to affect the proportion of fentanyl absorbed but fentanyl is highly protein bound and hypoalbuminaemia has been shown to be associated with lower serum fentanyl levels. Fentanyl is metabolised by CYP3A4 which exhibits reduced activity in patients with cachexia. Xerosis (dry skin) is commonly seen in patients with anorexia nervosa, likely also to be a factor for patients with cachexia and reduced skin hydration reduces fentanyl absorption. This evidence will be discussed further here.

**Conclusion:** Patients with cancer cachexia can have unpredictable responses to transdermal fentanyl and so extra care must be taken with its use.

**Abstract number:** P1-425

**Abstract type:** Poster

## Health Promotion in Palliative Care - Is it Possible?

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**Aim:** In Denmark it is considered good clinical practice to offer patients requiring palliative care an open access to hospitalisation. Research and clinical experience show, however, that open access per se is not always a guarantee for good palliative care in a hospital context, where the overall focus is predominantly on curing rather than caring.

**Approach:** The study took place in a Danish University Hospital at a regional centre for the surgical treatment of gynaecological cancer diseases. It provides a series of proposals as how to improve the organisation of palliative care in a hospital context, based on principles of early detection of palliative challenges.

**Results:** A health-promoting intervention that focuses on early interventions based on interdisciplinary collaboration and patient involvement was developed. The intervention followed the National Board of Health's programme for rehabilitation and palliation in relation to cancer. As such, it represents the implementation of basic level palliative care in terms of

Early network conversations with the patient and her family

A change in focus from treatment towards personal needs and wishes

Open access to hospitalisation

**Lessons learned:** Health promotion in palliative care has been shown to improve the activity

level and quality of life. The trend is that early detection of palliative challenges result in longer symptom-free periods, which allows patients to stay in their homes for as long as possible. Early detection of palliative challenges focuses on patient involvement. By involving patient and relative perspectives and challenge these with research-based knowledge about palliative care, it is possible to bring forth life as well as life quality, also in the palliative phase. The concept contributes to patient and family involvement, continuous training in healthcare communication, interdisciplinary collaboration, and in some cases it may prevent the need of specialised palliative care.

**Abstract number:** P1-426

**Abstract type:** Poster

## "All's Well that Ends Well": Or is it?

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Although palliative care traditionally started at the end of the treatment phase the modern concept encourages palliative care consultation at a much earlier stage of the disease process. Some would argue even at the time of diagnosis. Modern palliative care goes beyond death to endeavour to support relatives with significant bereavement difficulties. But what of long term survivors of cancer who a significant number have symptoms and symptom clusters very similar to palliative care patients with a limited life expectancy? When discharged from the oncology service how are these patients with significant symptoms managed?

There are approximately 13million cancer survivors in the United States, of which two thirds are more than five years post treatment. (65%). The majority are cancer free however a significant proportion are left with the sequelae of their surgical, chemotherapeutic and radiation treatments.

The aim of this study to determine by a literature review the prevalence of symptoms and symptom clusters in adult cancer survivors. Disease specific toxicities will be described. The five most common long term symptoms in cancer survivors include fatigue, difficulties in concentration, sexual function problems in both men and women, significant neuropathies and other pain modalities. Although the range of symptoms encompasses all of those seen in palliative cancer patients who are not in remission, and have limited life expectancy. In one study more than 50% of patients reported that they did not receive adequate medical help in addressing and remediating these symptoms.

As treatments improve so will long term survivors. The challenge to be faced is to design systems and protocols that address these problems so that they can adequately be managed in the primary care setting with the appropriate specialty consultation.

**Abstract number:** P1-427

**Abstract type:** Poster

## Palliative Care over Patients with Hemopoietic Diseases Hospitalised in the Department of Hematology, Poznan University of Medical Sciences (UMP) in Poznan in the Years of 2008-2014

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Patients with hemopoietic diseases require a number of diagnostic procedures aimed at defining clinical advancement and determination of prognostic variables. Evaluation of patient's general condition is also indispensable as well as examination of potential coexistence of other diseases. Based on the data, therapeutic decisions are undertaken. The activities aim at cure or at prolongation of patient's survival. In the years of 2008-2014, 10,083 patients were hospitalised in our Department including 30 patients (0,3%) who received palliative care. The patients ranged in age from 25 to 73 years (median value: 44,8), they included 14 women and 16 men. The most numerous were patients with acute myeloblastic leukemia (13 patients; 43%) and patients with non-Hodgkin lymphoma (7 patients; 23%). Acute lymphoblastic leukemia and chronic lymphocytic leukemia was diagnosed each in 4 patients (13%). In the evaluated group myelodysplastic syndrome with excess of blasts was diagnosed in one patient (3%). Also Hodgkin's lymphoma was detected in one patient (3%). Duration of hospital stay ranged from 5 to 131 days (median value of 63.1 days). In view of patients age, general condition, complications in the form of multi-organ failure and primary resistance to treatment, at a defined stage of treatment no further intense therapy was administered and the patients were referred to palliative treatment. However, they were not re-located to other hospitals or to the ward of palliative treatment but till the end of their life remained under care of the team of physicians, nurses and psychologists in the Department of Hematology. Care over the patients included first of all nursing-hygienic activities, analgetic drugs, both narcotic and non-narcotic, were administered, liquids were infused. The management, conducted by a multi-disciplinary team, warranted for the patients a relative comfort in the last days of life, as well as a dignified, peaceful departure.

**Abstract number:** P1-428

**Abstract type:** Poster

## Receiving Chemotherapy for Cancer in Later Life: A Comparative Study in Two Cancer Services

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**Contexts and goals:** Cancer death rate remains high- second cause of death. Chemotherapy increased the hope of cure and/or a longer survival. Therapeutic recent advances have frequently identified the cancer to a chronic disease under prolonged chemotherapy. However, there is little data available on the chemotherapy (CT) benefits in advanced stages of the disease.

**Method:** The collection of data from patients receiving cancer chemotherapy intravenously in the last weeks of life in 2013 was carried out using the databases of pharmacy services and medical information. The collection focused on two populations of patients with cancer : one in medical oncology (solid tumors of any origin) and the other in digestive oncology. Both services are distinguished by their further recruitment but also by the existence of a



Multidisciplinary Consultative Meeting (RCP) centered on supportive care in digestive oncology service.

**Results and discussion:** 85 patients died in medical oncology in 2012 and 35 in the service of digestive cancer. Within 30 days preceding the death, 40% received chemotherapy IV in Medical Oncology and 14% in the service department of digestive cancer. In the last 15 days of life, the respective rates were 36% and 11%. So it seems that chemotherapy IV longer be pursued in oncology.

**Limitations:** Types of different cancer, death occurring outside the hospital and CT oral ignored

**Perspective:** The role of RCP supportive care in help in identifying palliative time with suspension of CT is highlighted by the difference between these two services. Supportive Care CPR lead to ask a number of questions: What benefits expected in this patient? In terms of survival? Quality of life? What care proposals can be made to the patient? Patient involvement in these decisions - including the development of alternatives to continued chemotherapy actual- is all the more important that the expected benefits may be uncertain and/or marginal.

**Abstract number:** P1-429

**Abstract type:** Poster

### Nutritional Strategies in Head and Neck Cancer (HNC) Patients in Palliative Care (PC)

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**Background:** Weight loss, nutritional mark most visible in HNC patients, is multifactorial and very common. Malnutrition could be a treatment consequence, normally RT with QT, or due to cancer anatomical localisation; however, usually malnutrition is present before diagnosis. Nutritional Support (NS) in PC must be guided by the gold standard: give patient's comfort; personalised, oriented by a multidisciplinary team, which should include a nutritionist, according to patient's taste and preferences and talked to families; to contribute to their quality of life.

**Aim:** Develop a decision tree with NS strategies for patients with HNC, in PC.

**Methods:** Based on bibliographical research and clinical experience, identify which factors more contribute for non nutritional intake in patients with HNC, in PC.

**Results:** It was observed that the conditions that most affect the nutritional intake were: dysgeusia, xerostomia, dysphagia, odynophagia, obstruction, mucositis, nausea and vomiting, early satiety by anorexia, anorexia, chewing difficulties, diarrhea, constipation and loss of teeth. Almost all patients in the late stage of the disease, when they arrive to PC team, present Percutaneous Endoscopic Gastrostomy (PEG) or Nasogastric Tube (NGT) feeding that enables NS, not always tolerated. So: evaluate whether the oral feeding is tolerated, otherwise introduces hypercaloric nutritional supplements when chewing ability/swallowing is maintained. If not, ponders the PEG or NGT placement, and choose for complete polymeric formulas (standard/hypercaloric-normal/low volume tolerance, rich/low fiber- constipation/diarrhea) or semi elementary formulas. It should be emphasised that the NS is intended only to maintain, does not seek improvement of nutritional status.

**Conclusions:** NS in terminally ill patients stills a conflict factor between health professionals and careers/family. In PC, NS must always be present, as a measure of comfort and life quality for patient and families.

**Abstract number:** P1-430

**Abstract type:** Poster

### Facing the Challenge - A Retrospective Review of Head and Neck (H&N) Cancer Deaths within a Regional H&N Unit and a Specialist Palliative Care Unit (SPCU) in England

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**Background:** Up to half of all H&N cancer patients will die from their illness and require palliative support. End-of-life care is especially challenging due to the profound impact the illness and treatments have on different organ systems and the perceived risk of acute catastrophic events.

**Aim:** To evaluate mode of death and quality of care in the last weeks of life provided to H&N cancer patients within a regional H&N unit and a co-located SPCU in England.

**Method:** A retrospective case note review was used to collect demographic and clinical details for all H&N deaths between 2007 and 2012 at the two sites. 'Sudden death' (SudD) was defined as the mode of death being in a rapid or unanticipated manner. 'Expected death' (ExpD) was defined as the mode of death being gradual and anticipated. Analysis was conducted using descriptive statistics.

**Results:** There were 105 patient deaths (89 on the H&N unit; 16 on the SPCU). 29 were excluded due to missing records. Of the remaining 76 patients, 63 died on the H&N unit and 13 within the SPCU. SPCU patients were younger (mean age 63 years) compared with hospital patients (mean age 70 years). The majority of patients had stage III/IV disease (H&N unit 45/57 (78.9%) and SPCU 9/13 (69.2%).

33/76 (43.4%) patients had a SudD and 43/76 (56.6%) had an ExpD. Major haemorrhage was the most common cause of SudD (n=13) and carcinomatosis (n=17) or pneumonia (n=14) were the most common causes of ExpD. The Hospital Specialist Palliative Care Team were involved in 13/33 (39.4%) SudD and 34/43 (79%) ExpD, although this was often very close to death (mean 0.9 days for SudD and 1.4 days for ExpD) and despite 33 patients (43.4%) having documented pain in the last week of life.

**Conclusion:** Dying from H&N cancer can be very acute because of the unpredictable complications that can arise. Sensitive communication with patients and families about this eventuality as well as proactive palliative care involvement would help improve quality of care.

**Abstract number:** P1-431

**Abstract type:** Poster

### What is the Appropriate Time to Start Palliative Care in Different Cancer Trajectories?

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**Aims:** To define the optimal time to start palliative care (PC) during advanced cancer treatment.

**Methods:** The files of 1366 deceased cancer patients are analysed to calculate the progression free (PFS) and overall survival (OS) of the subsequent systemic therapies (1 to 11) since the diagnosis of advanced disease.

**Results:** The mean duration of the PFS drops progressively from 563 d. after the 1<sup>st</sup> therapy to 145 d. after the 10<sup>th</sup> therapy, but there are huge differences between the different cancer types. The PFS in digestive oncology decreases from 487d. to 303 d, further to 269d and 219 in the first 2 therapies to end up in 186 d. for the last therapy. For metastatic breast cancer are the first 2 therapies highly effective with PFS times of resp. 710 d, and 482 d.; while during all the further treatments (3<sup>th</sup> till 11<sup>th</sup>) there is a stable PFS of about 180 d. (range 166 - 207 d.). In neuro-oncological patients the 1<sup>st</sup> therapy results in a PFS of 461 d. and the effectiveness of the 2<sup>nd</sup> line therapy dropped to 100 d. Few patients in different tumor types with very specific cellular molecular expressions can respond better with a 4<sup>th</sup> or more very individualised therapy than with the standard regimens. This results in a wide variation of OS after the subsequent systemic treatments. Results in hematological, urological, respiratory and gynecological cancers will be given as well.

**Discussion:** There is a global decrease in PFS of subsequent systemic therapies for advanced cancers but the PFS and OS is very tumor specific and there are lengthy PFS for molecular diagnosis based new anti-cancer therapies in some tumor types. Thus the implementation of early PC has to become tumor specific, according to molecular diagnostic therapeutic modalities. This will be a huge challenge for oncologists and palliative care workers to introduce PC in time in cancers with such divers trajectories.

**Abstract number:** P1-432

**Abstract type:** Poster

### Satisfaction and Attachment Patterns in Cancer Patients Receiving Palliative Care Treatment

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**Background:** Attachment orientations in coping with illness are crucial in cancer patients. Furthermore, satisfaction with palliative care is essential for appropriate interventions.

**Aims:** To evaluate the relationship between cancer patients' satisfaction and attachment in a palliative care setting.

**Methods:** We studied 100 patients (x= 69.10 years old) suffered from cancer. The most frequent types of cancer were urogenital (34%), gastrointestinal (26%). Satisfaction and attachment patterns were assessed with: Famcare-P13 (consisted of 'information/interaction with health care professionals' and 'availability of care') and Experiences in Close Relationship Scale (ECR) (consisted of 'anxiety', 'discomfort with closeness' and 'avoidance'). Univariate and multivariate analyses evaluated the relationship between satisfaction and attachment.

**Results:** Significant comparisons were found between 'information/interaction with health care professionals' with metastasis (p< 0.009), chemotherapy (p< 0.0005) and hormone therapy (p< 0.005). Significant correlations were found between 'information/interaction with health care professionals' and cancer duration (p< 0.0005). 'Availability of care' correlated significantly with 'anxiety' (p< 0.035), 'discomfort with closeness' (p< 0.051), 'avoidance' (p< 0.007). A multiple regression model showed cancer duration (p< 0.0005), metastasis (p< 0.046), chemotherapy (p< 0.0005) and surgery (p< 0.012) as predictors of 'information/interaction with health care professionals'. Education (p< 0.040), anxiety (p< 0.021), avoidance (p< 0.056) were the strongest contributors of 'availability of care'.

**Conclusion:** Satisfaction, regarding patients' interaction with health care professionals depended on cancer duration and multimodality treatments. Patients' satisfactions concerning availability of their care were influenced by education, anxiety, attachment and avoidance.

**Abstract number:** P1-433

**Abstract type:** Poster

### New Palliative Treatment Strategy for Cancer: Enzyme-targeting and Radio-sensitization Treatment So-called KORTUC

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**Background:** It has been reported that influenced factors to radio-sensitivity for the tumor were cancer cell specific factors, cancer cell cycle, and environment of cancer cell. We thought the environment of cancer cell was artificially most likely changeable factor. Among the factors, hypoxia is a tremendous impact. It is generally known hypoxic cells resist radiation therapy, too.

**Aims:** We have utilised the theory of Kochi oxydol-radiation therapy for unresectable carcinoma (KORTUC) to create oxygen saturated situation. Irradiation becomes more effective for cancer by this method. We have experienced 61 KORTUC cases for 4.5 years. These cases were divided into breast cancers in 28%, lung cancers in 23% and rectal cancers in 13%. Most of all were metastatic lesions, for example, skin, lymph node, and bone etc.

**Methods:** KORTUC has not been spread in Japan, yet. This treatment has performed in only 3% of all. Our ethics committee provision decided three adaptation of KORTUC from January 2010: 1) irradiation resistance, 2) repeat recurrence, and 3) not effective by standard treatments. This radiation resistance of hypoxic cells is considered to acquire from 0.2 mm tumor in size. Oxygen saturated situation is from 2.5 to 3 times more effective than hypoxic case in irradiation. Radio sensitizer is component of both oxydol and hyaluronic acid which are essentially human body elements, too. Oxydol administration into the tumor resulted in

the reduction of antioxidant enzymes and the increase of oxygen. At last, oxygen saturated situation is created and irradiation becomes more effective.

**Results:** There was no harmful events in KORTUC. The therapeutic effects were good. KORTUC is thought a safety and effective option for cancer.

**Conclusions:** We believe that most cancer patients might release from any problems and get more freedom by KORTUC. We hope this new treatment-KORTUC will spread all of the world.

**Abstract number:** P1-434

**Abstract type:** Poster

## Infections Related to Central Venous Catheters in Palliative Cancer Patients

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**Introduction:** Infections related to the use of central venous catheters (IR-CVC) are complications with a high prevalence and potentially serious consequences.

**Objectives:** To determine the prevalence of these infections in palliative cancer patients (PCP), etiology and associated bacteremia and identify possible preventive measures.

**Methods:** Prospective observational study, a cohort of all PCP hospitalised for fever and suffered consecutively related bacteremia catheter between January 2011 and December 2012.

**Results:** 19 episodes in 16 patients were analysed. 3 two times. Mean age 63 (range 54-81). 17 wearied Porth-a-cath. One a drum and one a Hickman. 11 women. 9 Breast, 5 bowel, prostate and glad blade: 1 and one gastric, cervix, ovary, lymphoma. 6 with chemotherapy. Etiology of bacteremia and IR-CVC: coagulase negative Staphylococcus : 7; S aureus : 5; Pseudomonas aeruginosa : 2; Proteus mirabilis: 1; Escherichia coli: 1; S. epidermidis : 1; Klebsiella pneumonia: 1; Enterobacter cloacae: 1;

**Discussion:** catheter infections are cause of hospitalisation for fever in palliative patients. The gram positive bacilli bacteremia has been the most frequent process, followed by GNB and fungi. Early catheter lock allowed keeping them.

**Abstract number:** P1-435

**Abstract type:** Poster

## Engagement in Everyday Activities for People with Advanced Cancer at Home

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**Background:** For people with advanced cancer, the daily life is characterised by frequent and rapid changes as the illness progresses. These changes impact the ability to engage in meaningful everyday activities at home. It is suggested that engagement in everyday activities is a basic human need that add meaning to life and helps support and restore quality of life. There is limited knowledge on how people with advanced cancer experience their engagement in everyday activities at home.

**Aim:** To understand how engagement in everyday activities is described and experienced by people with advanced cancer at home.

**Methods:** A qualitative descriptive design was applied. Participants were consecutively recruited from a Danish university hospital. Semi-structured interviews were performed in the participant's homes. Questions covered aspects of engagement in everyday activities, e.g. activities of a typical day and of specific importance. Interviews were audio recorded and transcribed verbatim. A content analysis was performed.

**Results:** The sample comprised 74 participants (54% male), WHO Performance Scale: 1 (43%), 2 (47%), 3 (10%), mean age 68.3 years (36-89), 36% lived alone.

Preliminary results show that the participants spent most of the day at home and that functional limitations influenced their ability to manage the daily life. They experienced difficulties with and loss of meaningful everyday activities, e.g. leisure activities and social interactions with family and friends.

**Conclusion:** This study contributes with knowledge on the everyday activities of people living with advanced cancer at home. This knowledge can inform and strengthen the quality of future interventions focused on enabling engagement in the everyday activities that people with cancer find meaningful in order to enhance their quality of life.

**Abstract number:** P1-436

**Abstract type:** Poster

## Parenteral Hydration Therapy at the End of Life

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The use of parenteral hydration in terminally ill patients is controversial because it is unknown what the impact of this at the end of life. System Edmonton Symptom Assessment (ESAS) was developed to assess a variety of symptoms frequently reported by patients in palliative care regardless of their specific diagnosis.

**Methodology:** A descriptive study, in which patients were hydrated for 3 weeks and each evaluated the ESAS was performed; considering inclusion criteria, exclusion and elimination.

**Results:** A sample of 24 patients, of whom 14 completed measuring 10 abandoned by functional impairment, was obtained. The most prevalent symptoms and higher scores on ESAS were tired with a prevalence of 16% and an average intensity of 5 ESAS, poor appetite with an average of 16% and 4.9 ESAS, drowsiness 14%, 4.4 ESAS. Upon completion of the outline of the most prevalent symptoms hydrations were similarly fatigue averaging 18% and those of 3.3, poor appetite and 11% average of 2.1 and drowsiness ESAS averaging 14% and in those of average 2.6. Anxiety although it was not a symptom of high prevalence during measurements (7% down to 3% final), he was the one that most registered a decrease of intensity ESAS in those patients with this symptom at the beginning of the measurement, being 2.2 at the beginning and 0.5 at the end.

**Conclusions:** The prevalent symptoms in patients in Palliative Care for hydration schemes show a downward trend, which makes us think that the hydrations have a beneficial effect at least in the perception of symptoms experienced by patients and same tendency to decrease in intensity as anxiety symptom events suggests that condition moisturising effect on the emotional state of the patient. Measuring the severity of symptoms of patients who are palliative hydration schemes opens a new line of investigation as the moisturising effectiveness in these patients.

**Abstract number:** P1-437

**Abstract type:** Poster

## Why Does Advanced Cancer Kill? A Review of the Literature

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In the United Kingdom there has been a recent call for more research into the biology of dying and separately into prognostication models for those with advanced cancer. The aim of this work is to review the literature relating to the biology of dying in advanced cancer.

**Methods:** The first search looked or cause of death analyses, primarily from post-mortem series, for cancer patients to evaluate whether the cause of death of advanced cancer patients was actually already known.

Once the need was established a literature search using the following terms in EMBASE and MEDLINE was undertaken (Search 2):

((Death OR 'Cause of Death') AND (Cancer OR Neoplasm)) AND (Models, Molecular OR Molecular Biology OR Pathology, Molecular, OR molecular medicine)  
A further search for articles describing known mechanisms of cell death and their role in death of the organism as a whole (Search 3):

(Death OR Patient Death) AND (Anoikis OR Apoptosis OR Autophagy OR Necrosis)

**Results:** For patients specifically with neoplastic disease a meta-analysis of 240 patients with advanced cancer demonstrated that 16% of deaths were assigned to 'advanced disease' rather than known complications, such as infection.

Search 2 produced 197 articles. Three abstracts were reviewed and of those one paper was retrieved and read in full, and was found not to be relevant.

Search 3 produced 54 articles. Four articles were retrieved from five abstract reviews.

However none relate to potential mechanisms of dying in advanced cancer. The concept of phenotypic, defined as apoptosis of an entire organism is described, and mechanisms relating to ageing are discussed in three of the papers.

**Conclusion:** The underlying mechanisms behind the deaths of some patients with advanced cancer are not understood.

The negative results of the literature search suggest that the molecular biology of dying from advanced cancer is an area in need of study.

**Abstract number:** P1-438

**Abstract type:** Poster

## Teenagers Treated Like Children and Expected to Act like Adults

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**Aims:** Examine referral numbers of teenagers and young adults (TYA) with cancer to the hospice, is there a need for TYA to access this service. To assess whether the experience of cancer is different in TYAs than older adults.

**Method:** In 2012 I looked at referral numbers in an adult palliative care service provider (hospice) for 3 consecutive years 2009, 2010 and 2011 of TYA, identifying 1-3 per year. In September 2013 a teenager and young adult's clinical nurse specialist appointed for 1 year. We launched an information campaign raising awareness of adult palliative care services, establishing joint working partnerships. Set up monthly TYA days.

**Findings:**

- Total of 12 referrals TYA from September 2013 - September 2014.
- Initial conversations with TYA by acute staff
- Treatment is likely to continue until death.
- Rapid titration of opiates, likely high dose with adjuvant therapies
- Period of palliative care is likely to be short
- Attitudes and behaviours vary.
- Response by professionals needs to be prompt.
- Advance Care planning is complex.

**Conclusion:** TYAs symptom control/palliative care interventions alongside oncological

treatment changes the perception of palliative care. Young people tend to require higher analgesic doses and have complex pain management. The emotional and social needs of TYA with cancer are complex and vary considerably. Social isolation for this age group is debilitating, facilitating peer interaction is an important aspect of their care. We have established that joint working is likely to improve outcomes and could be measured with palliative care being seen as an extra layer of support alongside treatment. The perception of palliative care from health care professionals was of interest. The project was influential in changing perceptions and illustrates the benefits of developing shared care. This encourages health care professionals to question their own beliefs. Funding provided by The Daisy Foundation

**Abstract number:** P1-439  
**Abstract type:** Poster

## Antimicrobial Use in Patients with Advanced Cancer: The Experience of a Palliative Care Unit (PCU) in Rio de Janeiro, Brazil

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**Aims:** To describe the characteristics of antibiotic use in patients with advanced cancer at a PCU in Rio de Janeiro, Brazil.

**Methods:** This was a retrospective cohort study of patients referred to the PCU during the period of July to December of 2010. Main variables, abstracted from charts, included demographics, site and type of cancer, Karnofsky Performance Status (KPS), devices use, survival time and antimicrobial use.

**Results:** 870 patients were included. The mean age was 62 years, 52% were female and head and neck cancer was the most prevalent disease (28%). Twelve percent of patients were referred without previous cancer therapy. At admission at the PCU 38% had at least one invasive device and 59% had KPS  $\geq$  50%. The median survival was 48.5 days. The frequency of at least one course of antimicrobial use was 41%, corresponding to 646 courses. Average time of antimicrobial use was 8.1 days and in 15% of the courses they were maintained until the time of death. The enteral route was used in 60% of the courses. The most prescribed antibiotic was amoxicillin + clavulanate (41%). Head and neck cancer ( $p < 0.001$ ), no previous cancer therapy ( $p = 0.04$ ) and the presence of invasive devices ( $p < 0.001$ ) were independent predictors of the use of antimicrobials. Patients who used antimicrobials had a higher mean survival (131 x 69 days,  $p < 0.001$ ). Among patients who used antimicrobials, having KPS  $\geq$  50% was predictive of longer survival (HR = 0.55, IC95% = 0.44 - 0.69,  $p < 0.001$ ).

**Conclusions:** Antibiotic use was highly prevalent in this cohort. The higher survival among antibiotics users is may be explained by the fact that prescribers tend to restrict this class of drugs for patients with poor prognosis. Clear definitions of treatment goals and indications of antibiotic use in these growing populations are a challenge.

**Abstract number:** P1-440  
**Abstract type:** Poster

## Consideration of the 11-year History of Palliative Care for Patients with Advanced Gynecologic Malignancies at a University Hospital without a Palliative Care Unit and New Perspectives

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**Purpose:** Although our hospital has no palliative care units, we established a palliative care team (PCT) 11 years ago and have functioned as a palliative care consultation team. We have received over 300 requests for consultation for these 11 years. Our department makes the largest number of requests to the PCT of our hospital and we proactively request intervention by the PCT. In this study, we analysed our previous data about consultation.

**Method:** We quantified 78 items, to the extent possible, in patients who received intervention by the PCT and conducted a comparative investigation. The items included the patient background characteristics, condition at the time of admission, condition at the time of intervention, the differences between the two periods, changes in treatment, and final evaluation.

**Results:** Most of the requests (up to 96%) during the first 5 years were pain control. However, subsequently, requests for pain control came to account for about 80% later and requests for mental care and alleviation of other symptoms accounted for about 15%. In regard to pain control, improvement was seen in about 90% of the patients. In regard to alleviation of other symptoms also, improvement was obtained to some extent. However, concerning spiritual pain, only about 24% showed improvement after the intervention. In addition, the quality of palliative care improved with the introduction of CART and the Liverpool Care Pathway in recent years.

**Conclusion:** By earlier intervention, a variety of more effective care activities, including for mental care, alleviation of symptoms and terminal care can be provided in addition to pain control. One of the final goals of palliative care consultation is shifting to a home care and this has been smoothly implemented. However, spiritual pain is still at the opposite end of the scale, suggesting that the efforts for this problem will remain a challenge for the future.

**Abstract number:** P1-441  
**Abstract type:** Poster

## Management of Complications after Biliary Drainage Post Endoscopic Retrograde Cholangiopancreatography (ERCP) in a Oncology Palliative Care Unit

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**Case report:** A sixty-one years old female patient diagnosed with rectum adenocarcinoma with local and hepatic progression was submitted to oncologic treatment in 2007 with chemotherapy and neoadjuvant radiotherapy followed by surgical treatment. In 2009 a 4cm lesion in the fourth liver segment with invasion of hepatic hilum was found. There were no evidence of peritoneal disease or ascitis, and a non-surgical approach was chosen.

During 2012, patient presented jaundice secondary to tumor compression and percutaneous external-internal drainage was indicated.

On early 2014, patient evolved with new episodes of jaundice, abdominal pain and fever, suggesting cholangitis associated to obstruction of internal-external drainage. A metallic biliary endoprosthesis was allocated. Procedure was performed, after patient developed intense abdominal pain. CT scan identified sub-capsular hepatic hematoma measuring about 3x10cm and percutaneous drainage was indicated.

After control of symptoms and progressive recovery, catheter was removed and the patient was discharged.

**Discussion:** The hepatic subcapsular hematoma is a rare complication, usually under diagnosed in patients submitted to endoscopic retrograde cholangiopancreatography. ERCP is the exam most indicated for obstructive complications of biliary and pancreatic systems, with complication rates of 2-10% and low rates of mortality (0.5%-1%). Published data shows that conservative treatment in non-oncologic cases of iatrogenic injuries after invasive procedures has presented good results. In oncology palliative care units the doctors and team should beware to functional classification (Karnofsky scale), prognostic classification (PAP Score or PPI), beyond the symptoms to be controlled.

**Conclusion:** In such situations, functionality and prognosis shall be evaluated before indicating an invasive procedure. It is fundamental each case individual analysis, having in mind the main stay of palliative care.

## Non-cancer

**Abstract number:** P1-442  
**Abstract type:** Poster

## About a Case of Lateral Amyotrophic Sclerosis (LAS): A Multidisciplinary Intervention

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**Introduction:** LAS cases are non cancer palliative diseases that have an evolution between 3 and 5 years and reach the end of life dramatically, with difficult symptoms control and family exhaustion.

**Aims:** With this work we want to show the multidisciplinary interventions of health caregivers towards the patient and family, trying to give comfort and control.

**Method:** Data from clinical process and family and multidisciplinary team opinions.

**Case description:** Sixty years old male, that begins fatigue and weakness. After about 6 month he has the diagnosis of Lateral Amyotrophic sclerosis, bulbar form, with progressive respiratory failing, dysphagia, myopathy, difficult communication and family exhaustion. He was followed, during their last ten months of life at the unit of palliative care, with two periods of admission. During these periods all the palliative work team used their technical, scientific and emotional resources to overcome the struggle over suffering.

**Conclusion:** Suffering during a terminal disease is physical, spiritual, psychological, in one word is total. The multidisciplinary team must have the skills to offer the best care with comfort and partnership.

**Abstract number:** P1-443  
**Abstract type:** Poster

## Breaking the News of a Motor Neurone Disease (MND) Diagnosis: A Survey of Neurologists

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**Background:** Communicating the diagnosis of MND is challenging for both neurologists and patients. The manner the patient receives the diagnosis is acknowledged to be the first and one of the most sensitive steps in palliative care.

**Aim:** To establish a knowledge base of usual practice of breaking the news of an MND diagnosis in Australia, highlight differences and similarities in Australian practice compared to European practice guidelines (and also compared to the experience of patients and their families in a future parallel survey).

**Method:** A cross sectional study using postal surveys. Questions centered on how patients' consultations were conducted, personal experiences in giving the diagnosis, the communication plan and support for patients and education and training needs.

**Results:** 73 neurologists responded (50% of all neurologists or 80% of those who deal with MND). Mean age was 52 years, 77% were male, mean length of practice was 20 years and



16% worked in a multidisciplinary clinic. Median period between first clinical consultation and diagnosis was 4 weeks (range 1-26), and 68% required 2 consultations and a median of 20 minutes to convey the diagnosis (range 10-90). 78% were always able to give the diagnosis in a private space and 41% always able to avoid interruptions; 69% found communicating the diagnosis 'very to somewhat difficult' and 65% experienced high to moderate stress and anxiety at the diagnosis delivery. Follow up support was always initiated by 68% of respondents within 4 weeks from diagnosis with subsequent follow ups of 12 weeks interval; 73% referred to an MND association for information and ongoing support; 54% received no specific training for giving an MND diagnosis and respondents were very interested (38%) to somewhat interested (44%) in having best practice guidelines developed.

**Conclusion:** The data reflect some differences in practice and the presentation will conclude with a comparative alignment with best practice guidelines.

**Abstract number:** P1-444

**Abstract type:** Poster

## Using the Surprise Question in Renal Out-patient Clinics: How Many Patients Might Be in the Last Year of Life?

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**Background:** National guidelines recommend the identification of Advanced Kidney Disease (AKD) patients in the last year of life to enable advance care planning and improved end of life care. The Gold Standard Framework (GSF) Prognostic Indicator Guidance (PIG) exists to aid the identification of these patients and is a useful way to assess the potential demand in a given patient population.

**Aim:** To survey the renal outpatient population using GSF PIG at a large hospital trust to estimate the number of patients who might be in the last year of life. This represented a measure of demand as part of a quality improvement project.

**Method:** A proforma with GSF PIG prompts (including those for renal disease) was completed by the Consultant Nephrologist for each patient seen in renal clinic over a two week period. Other details included Stage of Chronic Kidney Disease (CKD), Diagnosis, Co-morbidities and current treatment for CKD.

**Results:** Of 152 patients in 15 clinics, 30 (20%) were identified as potentially being in the last year of life. The 'Surprise Question' (Would you be surprised if this patient were to die in the next few months, weeks, days?) was the most significant indicator. The majority of these patients had Stage 4 and 5 CKD, and the commonest co-morbidities were cardiovascular disease and diabetes. 30% of these patients were receiving conservative management for their renal failure.

**Conclusion:** Using GSF prognostic indicator guidance in a hospital renal out-patient setting was both achievable and relevant and identified a significant proportion (20%) of renal out-patients as being potentially in the last year of life. These findings will be used to inform service development of hospital and community palliative care for patients with renal disease and allow appropriate end of life care planning in keeping with patients' wishes and within published guidelines.

**Abstract number:** P1-445

**Abstract type:** Poster

## License to Perform Palliative Care - Nursing Practice in Medical Departments

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**Background:** In many countries approximately half of the population dies at the hospital making the general palliative care a central and necessary nursing task. General palliative nursing care in the hospital setting is recognised as challenging, however, little research has been done focusing on the actual practice.

**Aim:** To explore the nurse's perception and practice of general palliative nursing care at medical departments.

**Methods:** Ethnographic study, inspired by Spradley including observational field studies and interviews with nurses from three medical departments in a Danish regional hospital.

**Findings:** The nurses perceived the doctors as those who gave them *license* to perform palliative care to the patients. According to the nurses this happened far too late in the patients' illness trajectories - very close to the time of death. This *license* allowed a shift in the nurse's roles and gave them opportunities to provide care to the patients, described as *loving care*. However, *loving care*, had no commonly defined or approved content. Palliative care was regarded by the nurses as a valued task, but it was practiced individually and often without explicit knowledge or use of guidelines.

**Conclusion/perspectives:** General palliative care was not regarded by the nurses as a natural component of every day care for inpatients with life-threatening illnesses, but as a special concept of care for dying patients termed *loving care*. However, *loving care* had no expressed or approved content, making the practice of care fragmented and relying on the individual nurse.

**Abstract number:** P1-446

**Abstract type:** Poster

## The Need of Palliative Care for Patients with Rheumatic Diseases - Opinion of Rheumatologists

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**Background:** The World Health Organisation (WHO) recommends that conditions in which palliative care may be needed include i.a. rheumatoid arthritis (RA). However, patients with advanced rheumatic diseases are not referred to Polish palliative care centers. The benefits of providing palliative care for patients with terminal phase of RA at their homes, were observed by clinicians working in rural areas in Poland. There is an evidence gap in evaluating the need of palliative care for patients with advanced rheumatic diseases.

**Aim:** To assess the need of palliative care for adults with advanced rheumatic illnesses.

**Methods:** In a pilot study an anonymous structured questionnaire consisting of 9 questions concerning personal experience in treatment of patients with advanced rheumatic diseases was completed by 64 rheumatologists dealing with adult in- and outpatients in Poland.

**Results:** 97% of the respondents answered that palliative care would be beneficial for some of the patients with advanced rheumatic diseases (91% of respondents indicated RA, 48% - systemic sclerosis SSCL and 35% - systemic lupus erythematosus SLE). The most frequently reported distressing symptoms among RA patients were pain 94%, disability 72% and stiffness 38%. 63% of respondents indicated home as the place of death of adult patients with advanced RA. 58% of rheumatologists reported using mild opioids in more than 21% of patients. 27% of respondents have never treated their patients with strong opioids, 78% rheumatologists reported they had patients in terminal phase of rheumatic disease, but only 28% of respondents have ever consulted a patient with palliative medicine specialist.

**Conclusion:** In opinion of questioned rheumatologists palliative care would be beneficial for patients with rheumatic diseases (in particular with RA, SSCL and SLE). There is a need for collaborative efforts by the relevant organisations to supply palliative care for patients with advanced rheumatic diseases.

**Abstract number:** P1-447

**Abstract type:** Poster

## Phase 2 Randomised Controlled Trial of Future Care Planning in Patients with Advanced Heart Disease

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**Background:** Patients with advanced heart disease typically have a poor prognosis despite optimal cardiac therapy. These patients and families rarely receive coordinated holistic assessment and future care planning (FCP).

**Aims:** This Marie Curie funded phase 2 trial seeks to explore whether a FCP intervention is acceptable, feasible and deliverable to patients (and families) with advanced heart disease following a recent unscheduled hospital admission.

**Methods:** Patients with an unscheduled admission for acute coronary syndrome (ACS) or heart failure (HF) were screened using a prognostic scoring tool. Patients with a 12 month estimated mortality risk of 20% or greater were randomly allocated to either early (upon discharge) or delayed (after 12 weeks) FCP for 12 weeks. The FCP intervention combines holistic needs-assessment by a cardiologist with creation of a written/shared FCP and nurse-led care in the community. The primary outcome is quality of life of patients and carers assessed using questionnaires. Other outcomes include hospital readmissions, use of palliative care services, and preferred and actual place of death.

**Results:** We recruited 50 patients (32 carers) - 22% with ACS, 68% HF and 10% valvular heart disease. There were 5 deaths and 5 withdrawals. For the whole cohort mean age is 81.1 years (SD = 8.6), 60% male, mean Charlson comorbidity index was 4.2 (SD = 1.7), median Canadian frailty scale = 5 (mildly frail). Intervention and follow up is currently on-going and detailed findings will be ready for presentation by April 2015.

**Conclusions:** Findings from this small clinical trial demonstrate that the intervention and outcome measures were feasible and deliverable. Further analysis will provide invaluable information on the nature and feasibility of a larger clinical trial sufficiently powered to address hard clinical end-points.

**Abstract number:** P1-448

**Abstract type:** Poster

## Hospice Enabled Dementia Care

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**Aims:**

Identify existing good practice in dementia care within UK hospices.

Identify barriers for hospice in working with pwt.

Develop a model of hospice enabled dementia care.

Develop a resource to support and guide hospices in engaging with people with dementia and their carers.



Develop partnerships and collaborations for future work.

**Design:** Help the Hospices and Hope for Home, a UK dementia charity, collaborated on a year long project November 2013–November 2014 to achieve that aims above. The project was guided by a steering group of professionals and lay people from dementia and palliative and end of life care. A review of the literature helped to identify the scope of end of life care needs for people with dementia that hospices may wish to respond to or replicate. A survey amongst UK hospices was launched online to help establish existing good practice. Following the survey meetings were held with individual hospices to explore successes and difficulties in relation to supporting people with dementia and their carers.

**Results:** Twenty five hospices in the UK completed the online survey. Whilst we acknowledge this response was low, it did enable the development of some understanding of how hospices were trying to engage with and support people with dementia and their families. It also revealed what hospice consider are the barriers to engaging with and supporting this vulnerable group who could benefit from the range of skills and services hospice has to offer.

**Conclusion:** A number of hospices in the UK have already embraced dementia and reached out to people with dementia and their carers in many different and creative ways. However, a number remain anxious and hesitant with no clear guidance on how to do this and what to consider. The main output from the project is a resource that will guide hospices in taking the first steps into dementia care and beyond for those who have already embraced this important work.

**Abstract number:** P1-449

**Abstract type:** Poster

## Diabetes Management at the End of Life: The Experience at a Large Teaching Hospital

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**Background:** Current practice is variable with regard to the management of diabetes at the end of life.

**Aims:** To compare individualised end of life care plans of patients with diabetes against recommendations in the national guidelines 'End of Life Diabetes Care' (Diabetes UK, 2012).

**Methods:** Retrospective analysis of patient records of deceased adults for whom electronic end of life care notifications had been generated prior to death (excluding intensive care) in a teaching hospital over a 3 month period.

**Results:** Records of 108 deceased patients were included. 23 patients (21.3%) had a documented diagnosis of diabetes. All had type 2 diabetes, managed with diet, oral hypoglycaemic drugs, insulin or a combination of all three. Four of the 23 patients (17.4%) were on steroids.

20 patients were reviewed by the palliative care team 1 patient was reviewed by the diabetes team. 8 of the 23 diabetic patients (34.8%) had a documented plan for management of diabetes at the end of life, including capillary blood glucose (CBG) monitoring.

2 patients had an episode of hypoglycaemia (CBG < 3.5mmol/L) documented before death, and 3 had a documented episode of hyperglycaemia (CBG > 15mmol/L). Frequency of CBG monitoring followed guideline recommendations in 8 patients.

**Conclusion:** Diabetes was a diagnosis in nearly a quarter of anticipated adult deaths, but only a small proportion had a plan documented for this. These results suggest a need to improve diabetes education for palliative care teams and involve specialist diabetes teams when required.

**Abstract number:** P1-450

**Abstract type:** Poster

## Palliative Care for Patients with Non-cancer

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**Background:** The provision of palliative care for patients with non-cancer is limited in Japan, because palliative care for patients with only cancer and acquired immunodeficiency syndrome is covered by national health insurance. Therefore there are few detailed survey and information on palliative care for patients with non-cancer.

**Aims:** The aim of this study is to retrospectively investigate into clinical features and palliative care intervention by palliative care consult team (PCT) in patients with non-cancer. **Methods:** We reviewed all medical records of 276 patients who received palliative care interventions by PCT during their hospitalisation from May 1, 2013 to August 31, 2014 at our hospital.

**Results:** 30 patients (male 20, female 10) were reviewed in this study. The median age was 73 years (17–95). Sixteen patients were in general ward, and 14 patients were in critical care unit. Primary diseases were gastrointestinal diseases (n=9), respiratory disease (n=8), cardiovascular disease (n=5), renal disease (n=2), others (n=6). Reasons of consultation were pain (n=14), dyspnea (n=12), delirium (n=1), others (n=3). All interventions by PCT were use of opioids (n=22), palliative sedation (n=6), follow up (n=3), others (n=4).

**Conclusion:** Twenty of 22 patients who used opioids for pain or dyspnea were opioid-naïve. Many of Japanese physicians infrequently use opioids for patients with non-cancer, because use of opioids in Japan is governed strictly by law. It is necessary that PCT tell physicians how to use opioids for patients with non-cancer.

**Abstract number:** P1-451

**Abstract type:** Poster

## Meeting the Needs of Patients with a Non-cancer Diagnosis in a Hospice Environment

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**Background:** Patients living with advanced non-malignant conditions have a similar symptom burden to those with cancer; however access to palliative care services for this group is often poor. It was noted locally patients with non-malignant disease were under-represented within the hospice population. Cross-sector education of professionals regarding the role of specialist palliative care in managing advanced non-malignant disease was therefore undertaken.

**Aims:** To assess the change in referral patterns following the initiative to increase awareness of specialist palliative care for those with non-cancer diagnoses. To understand the problems identified in patients with non-malignant disease, and the outcome of initial specialist palliative care assessment.

**Methods:** Retrospective casenote analysis was undertaken of referrals to the hospice for patients with a non-cancer diagnosis over two 6-month periods, before and after the intervention to increase referrals to the hospice. A standardised data collection tool was used.

**Results:** The number of referrals increased from 13 over the first 6-month period, to 50 in the second 6-month period; 70% of patients had a respiratory diagnosis. The most prevalent problems identified after initial assessment were dyspnoea (79%) and low mood (48%). 58% of patients assessed were referred to the hospice day therapy service; 23% of those referred declined day therapy after their initial visit. At the end of the study period 43% of patients referred to the hospice had been discharged, the average time from referral to death was 106 days.

**Conclusion:** Through a targeted intervention we have been able to significantly increase referrals to the hospice for those with a non-cancer diagnosis. The burden of symptoms within this group of patients is high, with a clear need for the holistic support of the hospice environment. More work is needed to ensure hospice services are tailored to meet the needs of patients with a non-cancer diagnosis.

**Abstract number:** P1-452

**Abstract type:** Poster

## An Evaluation of the Dementia Patients Journey in the Specialist Palliative Care Service

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**Background:** Specialist palliative care at the end of life is much more available than it was 50 years ago. However there is increasing evidence that these patients with diseases other than cancer have difficulty accessing this specialist service (National Council for Palliative Care, 2007). Hospices may fear their services been inundated with referrals but they also worry about not having the right skills (Hughes et al, 2005).

**Methods:**

- A literature search was completed
- A retrospective case note review was carried out of referrals in 2012 to a Specialist Palliative Care Service. A structured questionnaire was completed.
- 10 healthcare professionals were interviewed to determine their experiences.

**Results:**

- 409 referrals were received in 2012
- 42% had a non-malignant diagnosis and 58% had a malignant diagnosis
- 15% (61) of patients were included in the study as they were referred with a primary diagnosis of dementia or had a co-morbidity of dementia.
- 44% of patients were referred by GP
- 51% of patients were located in the general hospital setting
- 36% of patients did not have a geriatrician or the psychiatry of old age service involved at the time of the referral.
- The main indication for referral was for symptom control of pain and confusion.
- 50% of the patients referred were involved in the service for 8–14 days
- 13% of patients died in the hospice in-patient unit
- The qualitative data analysis will be completed in November 2014.

**Conclusion:** Specialist palliative care for people with dementia is under researched. This gap in research mirrors a gap in practice. We do not know how transferable this is to Ireland. This project aimed to bridge the gap by illustrating the dementia palliative care patient's journey in a specialist palliative care service in Ireland.

**Funding:** This Study was funded through the Irish Hospice Foundations 'Changing Minds' Programme

**Abstract number:** P1-453

**Abstract type:** Poster

## Renal Palliative Care in Spain. An Epidemiological Approach

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**Introduction:** Certain patients with end-stage kidney disease (ESKD) can benefit more from conservative kidney management (CKM) than renal replacement therapy (RRT). An unestimated percentage of patients die after withdrawing dialysis. Early incorporation of renal palliative care (RPC) could improve their quality of life.

**Aims:** Identify and quantify the need for RPC in patients, stage 4 and 5 ESKD in Spain. Furthermore, describe the care that is currently offered and the degree of involvement of palliative care (CP) teams.

**Materials and methods:** A survey of the nephrology services that are registered with the Sociedad Española de Nefrología (SEN, Spanish Renal Society).

**Results:** 56% of the 190 hospitals responded to the survey (84% public, 7% private, 7% privately managed). A total of 10,835 patients were recorded. CKM is generally offered as an additional option for ESKD treatment. 45% of hospitals offer CKM. 9% of patients choose CKM, most due to functional deterioration, high comorbidity and 45% having been monitored for more than two years in consultation. 3% of dialysis patients die after withdrawing RRT, 75% of them in a hospital. In 35% of these withdrawals, no advanced palliative care plan has been developed, in 50% of these cases because no PC teams are available. 18% of patients receiving haemodialysis (HD) would not surprise their nephrologist if they died during the course of the next year ( $p < 0.0000001$ ).

**Conclusions:** One in four patients with ESKD will require RPC. The study results reveal certain epidemiological facets of patients with ESKD receiving CKM in Spain. They could form the basis for building specific RPC strategies that support Spanish Nephrology in resolving difficult situations specific to ESKD.

**Keywords:** Renal palliative care, conservative kidney management, dialysis withdrawal.

**Abstract number:** P1-454

**Abstract type:** Poster

## The Palliative Care Needs of People with an Intellectual Disability and Dementia: A Literature Review

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**Aim:** The WHO (2013) definition of palliative care outlines an approach to care for people with life threatening illnesses such as dementia. The aim of this piece of work was to establish, from the literature, the current situation with regard to the palliative care needs of people with an intellectual/ learning disability and dementia.

**Design:** A review of the literature was carried out by searching key terms on the databases CINAHL and PubMed, searching academic journals and non-academic grey literature websites along with recommendations from a person working in the intellectual disability sector. A total of sixty five documents made up of books, reports and articles were reviewed and information was synthesised by identifying prominent themes. The themes to emerge are: 'Decision making', 'Family/Next of kin involvement', 'Clinical symptoms' and 'Knowledge and skills of staff'.

**Results:** The literature indicates the following:

1. There are techniques that can be utilised to facilitate inclusion and elicit end of life care preferences.
2. Family members have bereavement needs that may require attention before the death of their loved one.
3. End of life symptoms are similar in the intellectual disability population to the general population. However palliative care staff express having a lack of confidence in adequately caring for people.

**Conclusion:** The evidence from this literature review indicates the requirement of, and will support the development of specific guidance for healthcare staff caring for people with an intellectual/ learning disability and dementia.

**Abstract number:** P1-455

**Abstract type:** Poster

## Are Lung Cancer Patients and COPD Patients Comparable?

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**Aims:** To compare two cohorts of patients suffering from lung cancer and COPD to establish their similarity and differences in order to plan palliative care approach

**Methods:** This is part of a larger study between the Respiratory Department and the Palliative Care team (PCT). Patient suffering from COPD and patients suffering from lung cancer at the first palliative care (PC) visit were able to take part after. The PC routine global assessment was performed and no intervention was considered different from the clinical practice.

**Variables:** socio-demographic variables; Edmonton Assessment system was completed; Functional assessment by Palliative Performance Scale Statistics: Descriptive analysis by central tendency measures and frequencies. Comparative analysis was performed by non parametric tests.

**Results:** 81 patients were included: 48 suffering from COPD and 33 from lung cancer. Mean age was 71.2; and 68.9 for each group. Male represented the 66% in the COPD group and the 81.8% in the cancer group. No statistic differences were found for age and gender. Mean number of symptoms were 5. Intensity was greater in pain, fatigue, anorexia, sadness, anxiety and insomnia in cancer patients; Dyspnoea was greater in COPD patients. We found statistics significance in: Pain, anorexia, dyspnoea, and sadness. Performance status was better in COPD patients. Only the 31% of the COPD patients needed PC follow up as outpatients or by the PC Home Team vs the 100 of the cancer patients.

**Conclusion:** COPD and lung cancer populations share some characteristics but they are not comparable.

**Abstract number:** P1-456

**Abstract type:** Poster

## Patients with Progressive Lung Disease Need to Know More about Palliative Care - Qualitative Longitudinal Study on Patient Perspectives

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**Background:** Chronic progressive lung diseases become increasingly important for palliative care as they are one of the main causes of death. Both lung cancer and COPD may lead to serious life threatening symptoms such as breathlessness or pain. Further patients often suffer from psychosocial burden.

**Aims:** The aim of this study is to explore the shift of the needs of patients with progressive lung diseases, and the needs of their family carers, over time.

**Methods:** Qualitative prospective longitudinal study; 4 interviews within 12 months with patients with advanced staged lung cancer and COPD. 2 groups à 20 p; interviews with family members. Analysis using grounded theory.

**Results:** First results show different consequences related to the experience of the diagnose setting: While those with lung cancer associate their diagnosis with lifetime limitation and loss of control, COPD patients often do not realise its life threatening consequences. During illness trajectory patients perceive medical treatment from different perspectives (burden vs. relief) and need group specific forms of therapy (e.g. physiotherapy, psychosocial support). Both try to delay nursing support by maintaining their autonomy and daily routine. Palliative care won't be used; instead, both patients revert to family care. Often it will be equalised with lifetime determining and death, therefore most patients avoid claiming palliative care.

**Conclusion:** During treatment, the implementation of accompanying psychosocial and nursing support is indicated for patients and relatives in both groups. An open professional approach for the needs of patients with progressive lung diseases, extensive information about the benefits of comprehensive psychosocial and general-nursing support can conduce to maintain the quality of life. An early informing by general practitioners with integrating palliative care can further relieve the home health care and reduce the burden of disease for patients and family members.

**Abstract number:** P1-457

**Abstract type:** Poster

## The Assessment of Cognitive Change in Motor Neurone Disease / Amyotrophic Lateral Sclerosis

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**Background:** There is increasing awareness of the prevalence of cognitive change in motor neurone disease (MND) / amyotrophic lateral sclerosis (ALS) with 15% of patients showing evidence of frontotemporal dementia (FTD) and evidence of other cognitive change - primarily frontal lobe dysfunction - in up to 50%. The Edinburgh Cognitive Assessment Scale has been developed to help identify people with cognitive change.

**Objective:** This study was to see if the ECAS could be undertaken within the normal clinic setting and to investigate the prevalence of cognitive change.

**Methods:** 10 patients were assessed during an extended outpatient clinic appointment or in the day hospice. Patients who had severe problems communicating, were anxious about their care and deterioration or were unwilling to be involved were excluded.

**Results:** 10 patients were assessed. 30% were male, the mean age was 62 years, the mean time from diagnosis to testing was 45 months and the mean ALSFRS-R score was 28. The ECAS was easy to administer and took 20-30 minutes.

Of the 10 patients one had previous evidence of severe cognitive change, with FTD. Four patients had results below the cut-off level for cognitive change and had not been considered as having cognitive change, although three were positive on a short test - and were not able to say at least 10 words starting with B in 1 minute. 3 patients were just above the cut off level.

**Conclusion:** The ECAS was easy to administer within a clinic or home setting and took on average 20 to 25 minutes and did identify people who showed evidence of possible cognitive change. This has enabled the team to be more aware of these issues and to be proactive in the discussion of issues of care including advance care planning. It has also allowed the team to share the results with carers and other professionals involved in the person's care to be aware of possible issues in decision making and help them cope with the deterioration of the patient's condition.

**Abstract number:** P1-458

**Abstract type:** Poster

## Development of Consensus Review on Palliative Care for Patients with Progressive Neurological Disease

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**Background:** A joint working group of the European Association for Palliative Care and the European Federation of Neurological Societies (European Academy of Neurology) collaborated in considering the available evidence for the palliative care in progressive neurological disease, including amyotrophic lateral sclerosis, multiple sclerosis, Parkinson's disease, stroke and primary brain tumours.

**Aims:** To produce a consensus paper aims, showing the important areas for consideration in the palliative care for people with neurological disease.

**Methods:** A literature search was undertaken looking at the main areas of palliative care and neurology. A review was formulated and this was then commented on by a small group and

then more widely until a consensus was developed.

**Results:** Seven main recommendations were agreed:

Palliative care should be considered early in the disease trajectory

The assessment and care should be provided by a multidisciplinary team approach, with access to specialist palliative care.

Communication should be open with patients and families and advance care planning is recommended.

Symptoms - physical and psychosocial - should be managed actively and appropriately.

Care needs should be assessed and carers supported before and after death. Professional carers should receive education, support and supervision to reduce the risks of emotional exhaustion.

There should be repeated and continued discussion about end of life issues and discussion of patients' wishes and aims - allowing appropriate management and intervention.

Palliative care principles should be included with the training and continuing medical education of neurologists and palliative care professionals should understand the issues for neurological patients.

**Conclusions:** This Consensus document aims to improve the care of people with progressive neurological disease and challenges all involved to extend these principles as widely as possible to support people with these diseases and their carers.

**Abstract number:** P1-459

**Abstract type:** Poster

## The Development of a Multidisciplinary Clinic to Improve Respiratory Care of People with MND/ALS

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**Background:** There is increasing awareness of the role of respiratory support for people with motor neurone disease (MND) / amyotrophic lateral sclerosis (ALS) to improve both quality of life and survival. In the UK the National Institute of Health and Care Excellence Guidance on the use of Non-invasive ventilation (NIV) in MND in 2010 suggested a multidisciplinary team approach and close collaboration between services. In Medway all patients attending the MND clinics are monitored regularly for the symptoms and signs of respiratory dysfunction and joint clinics have been developed including both palliative care and respiratory medicine, to discuss and monitor the use of NIV.

**Aims:** The aim of the study is to evaluate a new MDT approach for NIV.

**Methods:** The details and the outcomes of all patients seen within the joint palliative medicine / respiratory medicine clinic have been evaluated over a two year period.

**Results:** 9 patients have been considered over the last 2 years - 7 male, 2 female, mean age 55 years and mean time from first symptom to consideration of NIV was 25.5 months. 8 patients have started on NIV successfully at home - 20% of all the patients cared for with MND/ALS in the area - with repeated visits and support from the Specialist Respiratory Nurse, facilitating the use of NIV for patients who were initially very anxious.

**Discussion:** This joint approach has allowed people with MND / ALS to start NIV, with improvement in quality of life. The discussion has allowed a wider consideration of the benefits of NIV and the discussion of disease progression and the possible consideration of later withdrawal, as recommended by the NICE Guidance. The joint clinic has allowed a clearer approach to patient care with home commencement of NIV with a more comprehensive service to be provided with increased support of patients and their families and increased compliance with the intervention, leading to improved quality of life.

**Abstract number:** P1-460

**Abstract type:** Poster

## Biographical Rescue as an assistance proposal in Occupational Therapy to patients with Long Term Neurological Conditions

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**Background:** The care of people with Long Term Neurological Conditions (LTNC) isn't recognised in the Brazilian Palliative Care scientific production; in daily basis, the assistance is focussed on hygiene's care and clinical observation. However, from the perspective of palliative care, something more is needed, to promote the dignity of the human person.

**Aim:** To describe an occupational therapy intervention for patients with LTNC based on biographical rescue.

**Methods:** Records and field diaries of the first author were used to produce narratives and reflections about this intervention's methodology. The concept of Comprehensive Care is the main reference, designed as care interested in the existential sense of the illness process. It seeks to rescue the subjectivity of people with LTNC, understood as a way of organising all the meaningful different experiences in life.

**Results:** The beginning of the reconstruction of the patient's biography occurs by several perspectives, especially through sensory stimuli related to prior patient's occupational repertoire. Along with the detailed evaluation, the therapist does a careful and continuous monitoring, proposing activities, giving special attention to their reactions, being able to discriminate what pleases or not, and expanding the possibilities of encounter of people with LTNC and the environment which surround them. Therapist should also provide support and guidance to the family, which is in a vulnerable situation.

**Lessons learned:** Memory, history, identity, dignity, and subjectivity qualify the practice of occupational therapist with people with LTNC. Regardless of neurological reactions presented by the patients this practice helps reconstructing the meanings of the daily life of person with so severe disability. Sensory stimuli are shown as potential tools for a reconfiguration of the relationship with someone seriously affected by a neurological disease in Palliative Care.

**Abstract number:** P1-461

**Abstract type:** Poster

## Palliative Home Care - 15 Years of Experience of the Association of Palliative Care Volunteers in Wielkopolska

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We present the characteristics of palliative care realised between years 2006-2014 with patients who were under the care of our hospice. We analysed medical documentation of 1100 patients: 650 women and 450 men between 18-103 years of age. With patients with non-neoplastic diseases (54% of all reaserch participants) the direct reason for palliative care were: cardiovascular, neurodegenerative diseases, diabetes. In this group dominated patients over 70 years of age (81%); The majority were women (68,4%). The average time of care was 160 days. In the group of 519 patients with proliferative diseases the most important group of patients in the age over 60 years (79%) were looked after and observed for 65 days at average. Cancer most frequently concerned the lungs and bronchi, stomach, large intestinal, pancrea, brain and kidney (49%). Our experience proves that a lot of symptoms with the hospice patients towards the end of their life, independently from the type of disease, are the same. The main problemem with the patients is the pain. It occurs in 75% of all cases with cancer and in 68% of patients who suffer from non-neoplastic diseases. In neoplasia, the pain is severe, contrary to chronic diseases in which it is chronic and long-term and difficult to diagnose. Elder people suffer form a lot of kinds of pain of different intensity and location. It is connected with polyopathy. Individual approach to each patient is necessary. It is connected with specific spiritual and psychological needs and symptoms, which are hard to treat. Problems also occur in establishing the relationship and communication between the elderly and their guardian caused by hearing and vision problems as well as cognitive disorders. Our experience indicates that an increasing number of the elderly in recent time requires a better organisation and a new economic approach as well as and ethical changes in the organisation of palliative care in geriatrics.

**Abstract number:** P1-462

**Abstract type:** Poster

## "We Are all Sitting in one Boat - Knowing that it Will Sink" - Benefits and Limitations of Participating in a Self-help Group when Suffering from Amyotrophic Lateral Sclerosis

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**Background:** Self-help groups (SHG), as part of the system of lay help, pursue the goal of participants' mutual support in coping with an illness. In the case of amyotrophic lateral sclerosis (ALS), a fatal, progressive and incurable neuromuscular disease, the benefits and limitations of participating in a SHG have not been well explored.

**Aim:** To analyse the benefits and limitations of ALS-SHG described by participants, and how death and dying is dealt with in the ALS-SHG.

**Methods:** 13 qualitative, semi-structured interviews with 9 patients and 9 relatives from 3 different SHG in southern Germany (8 single and 5 couple interviews) were conducted in 2012. The interviews were transcribed verbatim and a qualitative content analysis was performed. **Results:** The benefits of the SHG were described as:

- 1) exchange of information and experiences,
- 2) orientation by learning from role models, and
- 3) sense of belonging to an understanding group of peers in contrast to a non-understanding environment.

The limitations of the SHG included:

- 1) burdensome encounters with other critically ill participants,
- 2) difficulties in communication and understanding due to dysarthria, and
- 3) a changing, heterogeneous group structure that prevents intimacy.

Although immanent and visible, the participants avoided discussing the incurable, progressive nature of ALS as well as death and dying. The attitudes of 'dealing positively with the disease' and 'staying active' were dominant, and there seemed to be little space for other forms of coping in the SHG.

**Discussion:** Death and dying seem to be a challenge for ALS-SHG. By attending the ALS-SHG, palliative care professionals could help to initiate a discourse about end-of-life issues and explain palliative symptom management - thus adding to the system of lay help. This way of supporting ALS-patients and families in dealing with topics surrounding quality of life and dying could become a further facet of Early Palliative Care for non-oncological diseases.

**Abstract number:** P1-463

**Abstract type:** Poster

## Situation in the Last Month before Death of Patients with Amyotrophic Lateral Sclerosis on Noninvasive Positive Pressure Ventilation

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**Background:** Unlike patients with cancer, those with amyotrophic lateral sclerosis (ALS) make decisions for their respiratory insufficiency. NPPV is effective to rest the respiratory muscles, to palliate dyspnea, and to prolong life. However, ALS patients use NPPV for 24 hours and recognise it as life-sustaining.

**Aims:** The purpose of this study was to clarify situations in the one month before death in ALS patients on NPPV who chose not to receive TPPV.

**Methods:** A total of 14 ALS patients died from 2011 to 2013 in Hospital A. Four patients were on TPPV, 5 were on NPPV, and 5 died naturally. Four ALS patients who died on NPPV and whose family provided consent participated in this study. Data were collected by retrospective medical chart review. This study was approved by the ethics committee of Hospital A.

**Results:**

**Patients' characteristics:** Two patients were in their 60s when they died, one in the 70s, and one in the 80s. Three were males and one was female. One had bulbar onset type ALS, and three had spinal type ALS. The time from diagnosis to death was 10 to 36 months. The duration of NPPV use was from 3 to 24 months.



**Situations from one month before death to death:** Communication ability on the ALSFRS-R score was 0 in two patients and 3 in the other two. One patient complained of dyspnea and felt panic in a painful situation, and another patient felt terrible torture and wanted to take off the mask. Pressure settings were changed in these patients from 0 to 10 times. Two patients had their mask type changed. All patients needed frequent sputum suction. One patient had a bed sore around the sacrum. Three patients used narcotic drugs.

**Conclusion:** This study clarified that ALS patients suffered from pain, from frequent pressure changes, and from the need for high pressure levels, and used narcotic drugs in the terminal stage. Further study is needed to accumulate data about the painful situation of ALS patients on NPPV in order to develop appropriate palliative care.

**Abstract number:** P1-464

**Abstract type:** Poster

## Provision of Specialist Palliative Care in Liver Services across the UK: Results of a National Survey

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**Background:** Liver disease is the fifth largest cause of death in the UK, but there is little strategy to improve care for those dying from it, as well as a lack of research in this area. Understanding of the views of health care professionals (HCP) on how care can be improved for patients dying from cirrhosis is poor.

**Aim:** To determine the knowledge base and practice patterns of a UK cohort of relevant HCP about delivering palliative care in cirrhosis, and to inform priorities for future research.

**Methods:** An on-line questionnaire survey was emailed to approximately 6000 HCPs working in hepatology and gastroenterology (liver), general practice (GP) and specialist palliative care (SPC) across the UK.

**Results:** 517 HCP responded (8% response rate): 195 from liver, 46 from GPs and 273 from SPC. Most liver and SPC HCP believed a role exists for SPC in caring for patients with cirrhosis, but 40% of SPC HCPs felt ill-prepared to provide good care to these patients. All HCPs wanted further training in: managing liver-related symptoms (SPC), symptom control and end of life issues (liver and GP). Although liver and GP HCP wanted to increase community provision of palliative care support, 46% of GP HCP felt unable to manage patients dying from cirrhosis in the community. Differences in the ideal time to refer were seen between liver and SPC HCP, where liver HCP were less likely to refer to SPC at symptom deterioration. Prognostication, symptom management and service configuration were key areas identified for future research.

**Conclusions:** Although all HCPs recognised the important role of SPC in caring for dying patients with cirrhosis, they all needed further training and uptake of skills to improve their confidence. Better joint working between SPC, GP and liver is needed to improve service delivery. Future research is needed to develop prognostic measures, better symptom management and a model for best practice.

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**Abstract number:** P1-465

**Abstract type:** Poster

## Chronic Non-cancer Pain in Life Limiting Conditions - An Area of Growth for the Palliative Care Specialty?

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**Aims or goal of the work:** Chronic non-cancer pain is a challenge but can be managed optimally with a multidisciplinary approach. Our study focuses on J, a 57 year old lady, who was admitted to our hospice for pain management. She has Kasabach Merritt syndrome complicated by chronic pain. Kasabach Merritt syndrome describes the association of haemangiomas with thrombocytopenia.

**Design, methods and approach taken:** During her admission, a multitude of therapies were initiated to improve her pain. Pharmacologically these involved opioid rotation from oxycodone to fentanyl and finally through to methadone. Sertraline was increased and anti-inflammatory agents tried. Psychosocial therapies included relaxation, hypnotherapy, psychotherapy and distraction therapies. Her management involved the whole multidisciplinary team based at the hospice with wider specialist input.

Furthermore, we made J the focus of our care rather than the pain, by concentrating on her interests and quality of life rather than her condition.

**Results:** J struggled to describe her pain or give it a reliable numerical score out of ten. We learnt to rely on other methods of judging improvement in her pain. Her facial expression changed over time with less grimacing and frowning. We noticed that the gap between analgesia breakthroughs increased from two to sometimes as long as six hours. She slept for longer at night without waking up for analgesia. Showering became a manageable procedure. She was discharged home with a subjectively better quality of life than on admission.

**Conclusion / lessons learned:** As hospice care changes from cancer patients in their last days of life to complex symptom control for longer periods in non-cancer patients, we will see more patients like J with complicated pain issues. Our work has shown that all members of the multidisciplinary team have a role in pain management. The medications we started were just a small part of this lady's pain management plan.

**Abstract number:** P1-466

**Abstract type:** Poster

## Neurogenic Dysphagia as a Marker of Mortality in Elderly Patients

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**Background:** Dysphagia is a clear indicator of terminal diseases and high probability of death.

**Aims:** To determine the degree of dysphagia, its origin, and the prognosis of patients in the Hospital de Barbastro to test who undergo volume-viscosity

**Methods:**

**Design:** Prospective study of volume-viscosity test from March 2013 to December 2013.

**Data collection:** Age, sex, Charlson index, Barthel index, date of the test, reason for request, test results in efficiency and safety, introduction of enteral nutrition (nasogastric tube or percutaneous endoscopic gastrostomy), discharge destination (home, nurse home, hospital or death). Subsequently telephone or outpatient at six and twelve month reviews.

**Analysis:** SPSS 15.0.

**Results:** Mean age 80+/-10 years, mean Barthel index 24.5+/- 18.8, average Charlson index 2+/-1.9, 56% male, 44% female; applicant specialty: Geriatrics 51%, Internal Medicine 23%, Neurology 25%, other 1%; reason for the test: 54.7% stroke, 24% dementia, 2.7% parkinsonism, 18.7% other; test result: negative 20%, positive 66.7%, 13.3% impossible; particular test result: volume tolerated: low 24%, middle 38%, and higher 38%; texture tolerated: liquid 28.6%, nectar 49%, pudding 22.4%. It is established enteral nutrition in 20% (SNG 16% and GEP 4%). Discharge occurs: home 42.7%, nurse home 22.7%, other hospital 24%, death 10.7%. Survival at 6 months 61.3%. Use thickeners at 6 months 22.2%. Presence of aspiration at 6 months 12%. Survival at 12 months 49.3%. Thickeners used at 12 months 24.2%. Presence of aspiration at 12 months 15.6%.

**Conclusions:**

1. High mortality in patients with dysphagia in a context of very poor performance status and high comorbidity based on a less than one year.
2. Patients with dysphagia should be included in the monitoring program.

## Palliative care for older people

**Abstract number:** P1-466a

**Abstract type:** Poster

## Geriatric Patient Treated at Home by a Palliative Care Team Support: Symptoms and Polypharmacy

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**Background:** There is a high prevalence of geriatric patients treated at home by a palliative care team support.

**Aims:** To determine whether treatment of terminal patients is appropriate to their symptoms, prioritisation to symptomatic treatments and presence of polypharmacy.

**Methods:**

**Design:** Prospective study from March 2013 to March 2014.

**Data collection:** Age, sex, previous and present Barthel index, Karnofsky, number of drugs, discharge destination, symptoms, presence of dementia and pressure ulcers, and drugs.

**Analysis:** SPSS 15.0.

**Results:** N=281, mean age 83.27+/-9.2, 56.2% female; mean previous Barthel index 32.5+/-30, mean present Barthel index 20.38+/-30.2; mean Karnofsky 54.17+/-24.6; high polypharmacy: 6.98 average drugs; high percentage of institutionalisation: 35.5%; exitus 26%, discharged by stabilisation 66.5%, hospitalised 6.8%; anorexia 31%, delirium 30.2%, pain 26.3%, insomnia 16.4%, anxiety 12.1%, depression 11%, dyspnea 10%, nausea 3.2%. Dementia in 60%, immobilisation 62.6%, presence of pressure ulcers in 16.8%. Inhibitors proton pump 57%, antidepressants 42.7%, diuretics 38.7%, antiplatelet drug 37.6%, laxatives 31.7%, benzodiazepines 28.7%, atypical neuroleptics 28%, paracetamol 24%, typical neuroleptics 19%, antiparkinsonian drug 14.7%, anticoagulants 14.3%, acetylcholinesterase inhibitors 14.3%, calcium channel blockers 13.6%, digoxin 12.5%, angiotensin-converting enzyme inhibitor 12.2%, antidiabetic drug 10.8%, statins 8.2%, corticosteroids 6.8%, memantine 6.8%, transdermal fentanyl 6.5%, insulin 6.1%, beta-blockers 5.7%, pregabalin 5.4%, gabapentin 5%, tramadol 4.3%, metazolol 3.6%, non steroidal antiinflammatory drugs 3.6%, valproic 2.2%, morphine 2.2%, buprenorphine 1.8%, oral fentanyl 0.7%, codeine 0.7%, and no case treated with oxycodone or hydromorphone.

**Conclusions:**

1. High polypharmacy in patients with severe functional impairment.
2. Absence of appropriate prioritisation to symptomatic treatments



Abstract number: P1-467  
Abstract type: Poster

## "Idealistic Notion or Complex Reality?" Using the Literature to Inform a Cross Sectional Survey to Explore Health Care Professionals' Perceptions of ACP for People with Dementia in the Long Term Care Setting

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**Background:** Evidence indicates that whilst older people may wish to plan ahead, often they are not given the opportunity to do so. Advance Care Planning is considered as key process that enables planning ahead to be achieved. Demographics indicate that there are an increasing no of people with dementia residing in nursing home settings. Staff in such settings have an important role in assisting with ACP, yet there is a deficit in understanding the issues from their perspective.

**Aim:** To examine the HCPs' perspectives of ACP for people with dementia in the LTCs.

**Methods:** A sequential explanatory mixed methods design incorporating 2 interrelated phases.

Phase 1: Systematic narrative review of empirical studies published between 2002-2014 yielded 14 relevant articles which focused on HCP's perspective of ACP for people with dementia in this setting.

Phase 2: A cross sectional survey to all nursing home managers (n=269) in a region in the UK.

**Results:** Within the literature there is considerable variation in HCP's perspectives of ACP. These were grouped under 4 key themes: Early integration and planning for palliative care in dementia; Ethical and Moral Factors; Communication and Education, Training and Knowledge. The validity of this evidence will be further refined through quantitative exploring involving registered nursing home manager's perspectives on ACP using a structured tool focusing on three domains; understanding, attitudes and practice, underpinned by the Theory of Planned Behaviour.

**Conclusions:** Despite evidence, albeit limited, that HCP's recognise the potential benefits of ACP, there is continued reluctance to engage. The inequality in terms of access to palliative care is central to this, with increased integration at an early stage vital. Greater understanding of HCP's perspectives on ACP in this complex setting will contribute to the development of appropriate educational support and improved care for people with dementia approaching end of life.

Abstract number: P1-468  
Abstract type: Poster

## Anticipatory Prescribing for Residents Approaching End of Life in Care Homes

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Common symptoms at the end of life include pain, breathlessness, anxiety, respiratory secretions and nausea. National end of life care strategies advocate anticipatory prescribing as a way to manage these symptoms. There has been little research on anticipatory prescribing in care homes. With more people living and dying in care homes, it seems relevant to understand anticipatory prescribing in this setting. To explore the viewpoints of healthcare professionals involved in anticipatory prescribing in care homes with a focus on barriers encountered in relation to the prescribing of anticipatory medicines, as well as recommendations for best practice. A qualitative study was undertaken using a framework approach in Lothian, UK. 12 semi-structured interviews were conducted with healthcare professionals who were involved in the prescribing, dispensing or administration of anticipatory medicines in care homes. While anticipatory prescribing was regarded as being beneficial in that it may reduce hospital admissions and allows residents to have a comfortable last phase of life, uncertainties surrounding when it should be initiated often results in residents not getting the medication until after symptoms appear. Experience and training aid in providing care home staff with the confidence they need to identify the onset of the end of life phase in residents. However high staff turnover and frequent manager changes make this challenging. The importance of establishing and maintaining trusting relationships between professionals and the ability to communicate effectively across boundaries was found to be the most significant facilitator. Even when all the structural conditions are in place, its success will only ever be as good as the relationships of the professionals involved allow it to be. Given the increasing number of people living and dying in care homes, it must be a priority to ensure that anticipatory prescribing is available without delay.

Abstract number: P1-469  
Abstract type: Poster

## Family Perceptions about 'Good' and 'Poor' Quality End of Life Care for People with Dementia

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**Background:** In England there have been many reports of 'poor' care received at the end of life. Concerns have been highlighted in some areas of England about the care delivered to older people and particularly people with dementia. Much of this has been revealed in reports from families.

**Aim:** To explore the meanings of 'good' and 'poor' quality end of life care for people with dementia, from the perspective of family carers.

**Method:** 46 in-depth interviews with family carers of people recently diagnosed with dementia, or who were currently caring for someone dying with dementia, or who were bereaved. Interviews were analysed using thematic analysis methods.

**Results:** Participants highlighted the central role they played as carers. This role was sometimes relied upon too much by professionals. This led to an over reliance on them as carers. They often felt unsupported in three domains of caring: 1) care management, 2) physical caring, and 3) managing the emotional and psychological demands of caring. Participants described their frustration at being left to coordinate the care for the person with dementia. They felt at times that they were the 'case manager' for the person with dementia, or 'chief executive' of the individual's life and affairs, losing their identity as a 'relative'.

Participants did not talk in terms of 'palliative care'. They spoke about more basic aspects to care at the end of life. Care for the person with dementia was thought to be lacking in many basic areas, in particular attention and compassion from nursing staff. Participants associated the decline in this with a change in the nursing role to one that is task focussed and 'paperwork heavy'.

**Conclusion:** Carers do not focus on the technical medical aspects of end of life care, but are more concerned with the interpersonal aspects of care. Carers of people with dementia need to be recognised as advocates for their relatives as well as being in need of support themselves.

Abstract number: P1-470  
Abstract type: Poster

## Opioid Prescribing in Elderly Patients with Renal Impairment

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**Background:** Elderly patients requiring palliative care input often have multiple co-morbidities, including renal impairment, which can pose challenges to their care. Normal serum creatinine does not always indicate normal renal function. No clear guidelines exist in the use of opioids in elderly patients with renal impairment.

**Aims:** To determine the prevalence of renal impairment in elderly patients referred to the specialist palliative care service (SPCS) in Our Lady of Lourdes Hospital, Drogheda over a 15day period and to review opioid prescribing in these patients.

**Methods:** All patients 65 years or older referred to the SPCS from 01/08-15/08/2013 were identified and a retrospective chart review performed. Estimated Glomerular filtration rate (eGFR) of less than 90 ml/min was defined as renal impairment and graded into mild (60-89 ml/min), moderate (30-59 ml/min) and severe (< 30 ml/min). Patient demographics, type of opioid used, indication for use, mode of administration, opioid rotation and opioid related adverse-effects were collated.

**Results:** Thirty-one patients were identified, 18 (58%) female. 19 (62.3%) had a malignant diagnosis. Morphine sulphate was the primary opioid used in 10 (32.2%). 5 (16%) had normal eGFR, with 8 (25.8%), 11 (35.4%) and 7 (22.5%) patients with mild, moderate and severe renal impairment respectively. 21 patients (67%) had serum creatinine within normal limits. Of those, 16 (76%) had eGFR < 90 ml/min. 8 (25.8%) developed opioid related side-effects, of those 7 (87.5%) had eGFR < 90 ml/min. All patients with adverse-effects required opioid rotation.

**Discussion:** The prevalence of renal impairment is high among elderly patients. eGFR measurement is superior to serum creatinine alone in assessing the degree of renal impairment. Clear guidelines in opioid prescribing in elderly patients with renal impairment may help to minimise opioid-related adverse-effects. Further research is needed.

Abstract number: P1-471  
Abstract type: Poster

## The Specialist Care of People with Intellectual Disability as they Grow Older

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**Background:** People with intellectual disability are growing older and there are increasing issues of associated age-related diseases especially dementia, particularly with dementia seen at an earlier age in Down's syndrome. A specialist residential home for older people with ID and multiple needs, including dementia, has been developed as one of the first specialist nursing establishment of its kind in the UK.

**Aim:** To assess the involvement of the residents in their care and their quality of life and level of socialisation.

**Method:** The residents were assessed using the Social Network Guide, which maps the residents social networks and social support, DEMQOL, which allows assessment of quality of life for people with dementia and the Resident Choice Scale, which assesses opportunities for self determination.

**Results:** 13 residents were assessed. The number of individuals in each resident's network was a mean 9.8 (range 3 to 20), the DEMQOL-Proxy gave a health-related quality of life score of mean 112 (range 107-120), the Resident Choice Scale showed scores of over 3 out of 5 for 16 of the 26 items, showing good involvement and that they were able to make day to day choices.

**Conclusion:** The social network for the residents was less than in other studies of ID where the average was 22 and only 2% of the contacts were from people outside the home. However the home would appear to provide care where the residents were able to remain involved with others, express control on many of their activities and have a good quality of life. Further studies are being undertaken to assess the staff involvement and views of the care involved.

**Abstract number:** P1-472  
**Abstract type:** Poster

## Disconnect: Residential Aged Care Staff and Bereaved Family Perceptions of Palliative and End of Life Care

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**Background:** Effective communication is a key component of both residential aged care (RAC) staff palliative care training and family understanding. However families of RAC residents are often unaware of the impending death of their relative. Lack of communication between facility staff, residents and their families therefore can result in problems in implementing effective care plans thereby impacting on the quality of care provided.

**Aim:** The aim of the study was to identify information gaps and unmet communication needs of both staff and families to inform future strategies for enhancing quality of care for RAC residents with palliative and end of life care needs.

**Method:** A mixed methods design was employed incorporating a survey of clinical staff (n = 431) in 52 RAC facilities in one urban district health board (Phase One) and in-depth interviews with a purposive subsample of 26 bereaved family members (Phase Two).

**Results:** Staff most often (38.1%) rated the care of residents who had died in the facilities as 'very good' (n= 164). However, two of the most frequently cited areas for improvement in resident care were the delivery of basic cares (11.8%), information access/communication (10.2%). Staff members indicated comfort with discussing end of life with both residents and families. However staff sometimes assumed that the change in status of a resident was obvious to a relative when this wasn't the case. Although the quality of care was reported by families to be good, perceptions of a lack of staff with training in mental health, failure to recognise the need for medical intervention in some cases and an abrupt end to communication with families upon the resident's death were noted.

**Conclusion:** The research highlights the need for a problem based experiential learning approach to palliative care education to improve communication between families and staff.

**Abstract number:** P1-473  
**Abstract type:** Poster

## An Undisputable Alliance: Specialist Geriatric Palliative Care Services

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**Background:** Technology and health systems have afforded European countries ever more aged populations with disabilities due to long standing pathologies that bring with them complex symptoms, particularly in the last year of life. WHO and scientific organisations recommend Specialist Palliative Care (SPC) input as an innovative approach which helps all round.

**Aim:** To analyse available scientific and local evidence to determine what constitutes best End of Life Care for the elderly considering all their needs and varying complexities.

**Methodology:** Demographic and situation analysis relating to existing Geriatric Domiciliary, Day Hospital and Inpatient units in a traditional geriatric hospital, together with evidence from Palliative Care Geriatric Referent Professionals documents.

**Results:** Our region has high immigration and economic development with a 15% aging index and very high of over people 80 (4.4 % in 2011). Our Geriatric Home Care Teams sees some new 600 patients per year 30% of which over 85 have palliative care needs. About 10% of all geriatric admissions are advanced dementias. The highest peak use of the 24 hour platform are 80-90 Many of the professionals have received advanced training in PCAvailable data point towards a beneficial outcome of joined up best geriatric care supported by adapted palliative care support. It promotes continuity of care across all care settings avoiding unnecessary casualty visits and unplanned admissions.

**Conclusion:** Despite the wide range of geriatric and Palliative Care provision in our city, this study highlights the need for a new model integrating health and social resources to satisfy all EoL needs, whatever their complexity. A tertiary reference center will help raise the profile of our changing society and allow for further training and research.

**Abstract number:** P1-474  
**Abstract type:** Poster

## Project Dignity - Developing a Palliative Homecare Service for Patients with Advanced Dementia

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**Introduction:** Singapore bears the unique distinction of having one of the fastest aging populations in the Asia-Pacific region. In epidemiological studies, the prevalence of dementia ranges between 2-14%, with the prevalence expected to increase. The population of patients suffering from advanced dementia approximates 3000 a year, of whom at least half will spend their last days within a long term care institution. In Singapore, only 4.1% of the referrals to the largest palliative homecare service in 2013 was for advanced dementia support.

**Goal of study:** The primary objective is to develop a homecare hospice programme with disease specific skills to support advanced dementia patients and their caregivers. The secondary objective is to measure its cost effectiveness.

**Methods:** Prognostic criteria for entry into the pilot homecare programme was determined after literature review. Clinical assessment tools used in the programme were selected based on evidence supporting its use and its practical application in homecare. Cost effectiveness is evaluated prospectively from the cost savings of reducing average length of stay in the hospital.

**Results:** Patients with advanced dementia staged at Functional assessment staging of dementia (FAST) 7A, with at least another criteria in the form of either pneumonia, albumin < 35g/L or a feeding tube were eligible for the homecare programme. Patients were assessed using the 'Patient Care Bundle', comprising the PAINAD, the NPI-Q and the MNA. Caregivers were assessed using the QUALID and the Zarit Burden interview, part of the 'Caregiver Bundle'. At the end of life, patients were evaluated using the 'End of life' care bundle, involving the SM-EOLD, CAD-EOLD and SWC-EOLD.

**Conclusion:** Advanced dementia is still under-recognised as a terminal illness requiring palliative support. Supporting patients and their caregivers in the home with a homecare programme designed to meet their needs is the first step to addressing this gap.

**Abstract number:** P1-475  
**Abstract type:** Poster

## Attitudes, Knowledge and Educational Needs Concerning End-of-Life Care among Professionals at Nursing Homes in Denmark

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**Background:** In western countries, approximately one quarter of all citizens die at nursing homes. Studies have shown that end-of-life (EOL) care at nursing homes (NH) is suboptimal due to lack of knowledge among professionals. However, knowledge is needed if professionals at NH themselves think they need education in EOL care and if these needs and attitudes are associated with a general job satisfaction.

**Aim:** To describe attitudes, knowledge and educational needs concerning EOL care among professionals at NH and if these factors were associated with general job satisfaction.

**Method:** A questionnaire was developed in an interdisciplinary group and pilot tested among five NH professionals. The questionnaire will be sent to all professionals working with citizens at two other NH in Aarhus, the second largest city in Denmark, during October 2014. Questions were developed concerning attitudes, knowledge and educational needs concerning EOL care inspired by observational studies at two NH, previously developed questionnaires to professionals and literature studies. The last question of the Warr-Cook-Wall job satisfaction scale was also added: 'Taking everything into consideration, how do you feel about your job?' Descriptive analyses will be performed together with relevant regression analysis in STATA 13.

**Results:** The pilot test showed that the questionnaire was applicable and that the professionals found the questions relevant. The final results including associations between attitude and job satisfaction will be presented at the conference.

**Conclusion:** The final results of this study may indicate a need for optimising attitudes and knowledge of EOL care among professional at NH in Denmark. The results will be used as baseline data for a subsequent intervention study to optimise EOL care at Danish NH.

**Abstract number:** P1-476  
**Abstract type:** Poster

## Do We Have an Effective and Informed Workforce to Care for Those Living with End Stage Dementia within a Care Home Setting?

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**Introduction:** In line with the National Dementia Strategy (2009), a mixed methods programme was designed to develop and pilot a complex intervention to improve end of life care for people with advanced dementia. To do this, a facilitation-based model was adopted to provide education, training and support to health care professionals (HCPs).

**Aims:** However, to inform intervention development, we conducted a series of qualitative interviews to examine and understand the level of training and support in place for this workforce and where more training and education was required.

**Method:** A topic guide was used to interview 14 HCPs including commissioners, care home managers, nurses and health care assistants. We used a rigorous approach to data analysis, working to the quality framework recommended by Spencer et al (2003). Thematic analysis was used to analyse the data for meaningful themes.

**Results:** Themes suggested that staff training is needed in areas such as knowledge about dementia, managing dementia and providing compassionate care. Importantly, due to the emotions triggered by regularly dealing with death, staff require training and support on

how to manage death and dying and how to provide optimal care at the palliative stage of the disease. We found a need for online support and education, training on documentation processes and more funding for professional development. In addition to training staff working within care homes, we found a need for the training and assessment of HCPs from general practice who regularly care for those living with dementia in care homes.

**Conclusion:** Although the Government set out to upscale the skills and training of the workforce who care for those with dementia, the findings of this study suggest that not enough has been done to ensure that they have the relevant skills and knowledge to provide optimal care to those at the palliative stage of dementia.

**Abstract number:** P1-477  
**Abstract type:** Poster

## An Advance Care Planning Educational Intervention for People with Early Dementia

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**Aim:** Developed specifically to address advance care planning issues with those with a new diagnosis of dementia and their carers. Intervention enabled through interagency collaboration between mental health services, a local dementia specific charity and a specialist palliative care service.

**Design, methods and approach taken:** Designed with the support of an expert group of people with dementia. Delivered as a two hour group session titled 'Planning Ahead' (part of a five session course for safely exploring dementia related issues.) The session includes an introduction to advance care planning, with a focus on changing ability to communicate and make decisions about the future. We use a rights-based approach in discussion about the legal framework and provide support tools. Promotion of choice includes: place of care, preferences, hopes and wishes, and nature of medical intervention. One facilitator accompanies the group throughout the five sessions. The palliative care social worker joins this facilitator to lead on the future planning session. Group activities and discussion enable individuals to consider and acknowledge their own experiences and concerns.

**Results:** People with dementia and their accompanying family members report improved understanding about decision making in the event of changes in communication or capacity. They report a better understanding of why, when, how and with whom to make plans. Evidence exists that these conversations are difficult to start. Through group facilitation and peer support, issues raised by group members are normalised. Universal relevance.

**Conclusion:** Advance care planning is a cornerstone of specialist palliative care. Developing bespoke ways to meet the varying needs of different patient groups and their families is essential. Providing safe opportunities for people with dementia and their families to explore issues they may face in the future empowers people to access services when they require them.

**Abstract number:** P1-478  
**Abstract type:** Poster

## Needs, Wants or "Common Sense" - What Drives Decision-making about Care in Later Life for Older Adults?

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**Aims:** In an era where patient choice is deemed an integral component of medical decision-making particularly in relation to end of life and place of care, the uptake of advance care planning remains relatively poor. The reasons for this are complex, often resulting in delayed delivery of dignified palliative care to older people. Thus, we set out to determine if older adults have made plans of future medical care should they not be able to care for themselves, and if they may find it easier to make these decisions by focusing on their personal values and priorities. A secondary aim was to determine if this cohort had common values to guide health professionals when facing such dilemmas.

**Methods:** A postal questionnaire was sent to 710 community dwelling older adults in Manchester and Newcastle. Participants were asked to consider hypothetical situations regarding changes in lifestyle or place of care. They were also asked to rank a list of personal priorities in terms of how they might wish to be treated in the future.

**Results:** There was a 78.7% response rate. Majority of respondents (65.5%) had not made specific plans relating to their future care. Decision-making appeared to be more difficult when the degree of personal change required was greater. Only slightly over half were able to rank their priorities in a meaningful manner. For them, 'altruism' (what is best for their loved ones) was the most important factor, followed by 'kindness and compassion' and 'personal choice' in influencing decision making about their future care.

**Conclusions:** Decisions on one's important personal values can be as challenging as decisions about future care. Many older adults do not routinely consider these issues; nevertheless, would like to be involved in these decisions. Thus, it is vital to engage patients early on in advance care planning, especially in primary care, on how they wish to be managed over the course of their lives, with active involvement of loved ones.

**Abstract number:** P1-479  
**Abstract type:** Poster

## Intensive Care Unit [ICU], Biotechnology and a Moral Dimension for Palliative Care [PC] in Elderly Persons with Cancer: Assessment Criteria for PC

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**Background:** The sophistication of biotechnology has given doctors an enormous array of resources to manage acute conditions of patients, but the medical act has lost some of the empathetic dimensions. Palliative Care brings to light the moral dimension of care, and greatly reduces patient suffering.

**Aims:** To provide insight regarding the need for PC assessment for elderly patients with cancer admitted to the ICU, as a moral principle of *Utilitarianism*

**Methods:** Demographic and outcome information were recorded prospectively for elderly patients (≥65 years[ly]) with cancer in a general ICU. Data was collected for prognostic scores of acute illness (SAPS3,SOFA), comorbidity indices (Geriatric[GCI] and Charlson comorbidity index[CCI]), performance status (PS)[Karnofsky Performance Status(KS)], Palliative Performance Status[PPS] and Center to Advance Palliative Care criteria for PC assessment at time of admission [PC1] and during hospital stay [PC2]. Mann-Whitney/chi-squared tests; Spearman correlation were used to analyse data.

**Results:** 71 patients, median of 77±7y were enrolled during 8 months. Gastrointestinal (26/71;37%) cancers were the most common. Prognostic scores and comorbidity indices did not differ statically between discharge (32/71;45%) and death outcomes (39/71;55%)(SAPS3 p=0.31;SOFA p=0.41;CCI p=0.85;GCI p=0.94). PC1 correlated to prognostic scores (SAPS3 r=0.236 p=0.047;SOFA r=0.263 p=0.027). PC2 correlated to PS (KS r=-0.413 p=0.0003;PPS r=-0.505 p=0.0001) and prognostic scores (SAPS3 r=0.321 p=0.006;SOFA r=0.343 p=0.003).

**Conclusions:** PS and prognostic scores have shown correlation with criteria for PC assessment of elderly patients with cancer admitted to the ICU. The *Utilitarian approach* is in tune with the PC philosophy in that procedures are applied based on ethical values. It seems coherent to consider an alternative approach to care rather than the typical response of life-prolonging interventions for the chronically ill patients presenting in the ICUs.

**Abstract number:** P1-480  
**Abstract type:** Poster

## Assesment of Symptoms and the Process of Adaptation to the Diseases in Palliative Oncogeriatrics Field

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**Background:** Palliative oncogeriatrics has an important role in optimising the treatment of elderly patients with cancer.

**Aims:** To identify the principal sympyoms and the adaptation to the diseases of older patients with cancer, in order to asses their palliative care needs.

**Methods:** Design : Cross-sectional

Out of 180 consecutive old patients who have been admitted into the Department of Oncology- Palliative Care, over a period of four weeks, 70 patients were enrolled in the study. 110 patients were excluded based upon cognitive deficits or based on their functional status.

Face-to-face interviews were conducted using the Needs Near the End-of-Life Screening Tool (NEST)-Item 10, and Edmonton Symptom Assessment Survey (ESAS).

Data collection, analysis: the data were collected by hand and later stored in SPSS 20.0 and analysed.

**Results:** Mean age was 71,2 years .

This study indicates that the most important 3 symptoms are: fatigue (all the time: 62,86%, frequently: 25,71%), breathlessness (all the time: 57,14%, frequently: 17,14%) and nausea (all the time: 45,71%, frequently: 17,14%).

60% patients are never satisfied with them self as a person now, than they were before the illness, and 14,29% patients are rarely satisfied with this situation:

**Limitations:** Patient sampling was not representative of all, older cancer patients , being too small, but we believe this is a step in the design of a palliative care intervention which will increase the quality of life.

**Discussion/conclusions:** Old patients with cancer require assessment and treatment of burdensome symptoms, as well as access to services that address to their psychological needs.

Future work should focus on the role of oncogeriatrics medicine and palliative care in addressing these needs in order to achieve the best possible outcomes.

**Keywords:** Palliative oncogeriatrics, assesment, symptoms, adaptation



**Abstract number:** P1-481  
**Abstract type:** Poster

## Geographical Variation in the Percentage of Time Spent at Home or in a Community Setting Compared to Hospital for People Dying of Cancer during the Last 6 Months of Life

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**Background:** One aspect of good end of life care is supporting people in their preferred place of care. This study explores the geographical variations in the percentage of last six months of life spent at home or in a community setting, using a measure originally developed by Information Services Division (ISD) in Scotland.

**Method:** ONS mortality and Hospital Episode Statistics data (2010-2012) was used to determine the total time spent in hospital during the final 6 months of life for people dying from cancer. Excluded were persons in specialist, community or mental health hospitals and people with an external underlying cause of death (not falls). Geographical variation was compared to the Income Deprivation Affecting Older People Index (IDAOP) using a Spearman Rank Test.

**Results:** Across England people dying from cancer spent an average of 21 days in hospital during the last 6 months of life with Londoners spending most time (an average of 24 days) and people in the South West of England the least time (18 days). Across Clinical Commissioning Groups, up to 30 days difference was observed for all cancers, with a high of 60 days for bladder cancer and a low of 21 days for lung cancer.

A statistically significant association ( $p=0.001$ ) was found between the percentage of time spent in hospital during the last 6 months of life and income deprivation with people in the least deprived areas of England spending 3 days less in hospital compared to those in the most deprived areas. This level of association varied with cancer type, malignant melanoma showing the lowest level of association ( $R^2=7.2\%$ ,  $P=0.01$ ) and prostate and colorectal cancer the highest correlations ( $R^2=25\%$ ,  $P=0.001$  and  $R^2=24.4\%$ ,  $P=0.001$  respectively).

**Conclusion:** The amount of time people dying from cancer spend in hospital during their last six months of life varies depending on where they live and by levels of income, although this does not imply a difference in the quality of care at the end of life.

**Abstract number:** P1-482  
**Abstract type:** Poster

## Palliative Care for Prisoners: Findings from Phase 1 of the 'Both Sides of the Fence' Study

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**Background:** The Prague Charter advocates access to palliative care as a human right, and many countries are working to overcome challenges in providing appropriate palliative care for specific populations such as prisoners. In the UK, the need to improve palliative care in prisons is increasingly urgent; the prison population has doubled over the past decade, with men over 60 the fastest growing group. Many older prisoners have multiple and complex healthcare needs and will die in custody.

**Aims:** The 'Both sides of the fence' study aims to devise a model of integrated palliative care that can be shared with other prisons.

**Methods:** Using a participatory action research design, Phase 1 consisted of a detailed analysis of palliative care provision in one prison that has a high number of older and disabled prisoners. Data were collected through in-depth interviews with staff both inside and outside the prison ( $n=29$ ), focus groups with prison healthcare staff, security staff and prisoners ( $n=6$ ) and a case study centred on a prisoner approaching the end of his life. A detailed thematic analysis of all data was undertaken.

**Results:** Findings reveal that although there is great willingness amongst staff to provide high quality palliative care, prison regime and resource constraints present substantial challenges. Study participants reported difficulties with timely and appropriate medication (especially pain control) and continuity of care. Both staff and prisoners felt that prisons are not currently equipped to meet the needs of older prisoners approaching the end of life. There are also considerable emotional costs to staff, particularly security staff, in providing care in a custodial environment.

**Conclusion:** The study uncovered areas for improvement ranging from early identification of prisoners with palliative care needs to training and support for staff. The next stage of the study involves collaboration with staff to make and evaluate improvements.

**Abstract number:** P1-483  
**Abstract type:** Poster

## Large Differences by Local Area in Need for End of Life Care for People Aged ≥ 85 Years in England

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**Background:** The oldest of the old ( $\geq 85$  years) have very different needs in terms of end of life care from younger adults. The causes of death and place of death differ. People aged over 85 years are often extremely frail and have multiple health problems. Many have reduced mental capacity and many live alone. England is divided into 353 Local Authorities which have widely varying demographics. In planning for EoLC for people aged  $\geq 85$  years they need to consider the local demographics and what is known about place of death hospital admissions and causes. Local Authority Profiles are available to assist.

**Aim:** To examine, using routine data, the degree of variation in indicators of need for EoLC in people aged  $\geq 85$  years by English Local Authority/Methods Analysis of Routine data from the Office for National Statistics (ONS) and national Hospital Episode Statistics (HES).

**Results:** A selection shown as England Average, Lowest Local Authority, Highest Local Authority:

% Population 85+ 2.2%, 0.9%, 4.0%

% Male 85+ 1.0%, 0.7%, 2.8%

% Female 85+ 3.0%, 1.0%, 5.2%

Projected % increase in 85+ to 2033 142.1%, 24.5%, 233.7%

% All terminal admissions to hospital aged 85+ 37.8%, 27.5%, 49.4%

% deaths from dementia 17.3%, 7.9%, 26.9%

**Conclusions:** In planning care for the oldest of the old Local Authorities need to consider their local demographics and the impact this has on age at death, place of death and causes of death and how this will determine optimal provision of care. At present, for example provision of care homes varies by Local Authority but not in relation to potential need.

**Abstract number:** P1-484  
**Abstract type:** Poster

## Clinical Predictions of Survival - A Systematic Review of Accuracy, Expertise and Heuristics

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**Background:** Despite the existence of validated predictive tools, the most common method of predicting survival in palliative care patients remains simple clinical estimation. Previous reviews have reported that clinicians' estimates are inaccurate and over-optimistic. We wanted to identify whether some clinicians are more 'expert' at prognosticating than others and what rules (or 'heuristics') clinicians use to formulate their predictions.

**Aims:** To determine the accuracy of clinician predictions of survival in palliative care patients; to identify whether any sub-groups of clinicians could be considered more 'expert' than others; to identify the heuristics that clinicians use to formulate their predictions.

**Methods:** We used systematic review methodology to identify and classify relevant papers from MEDLINE, CINAHL, EMBASE, and the Cochrane Library. We identified 3,613 articles and 44 papers were included in the final review.

**Results:** 40 papers compared clinical predictions versus actual survival. Clinical predictions were 'accurate' (neither optimistic nor pessimistic) in 38% of cases (range 10-79%).

Seventeen papers compared the accuracy of different health care professionals (HCPs); 7/10 papers suggested that some HCPs (usually defined by profession or by experience) were more accurate than others. Only two articles reported the heuristics that clinicians employed; these included factors such as performance status, co-morbidity, rate of decline and spiritual state.

**Discussion:** Our review confirmed that clinician predictions are inaccurate. We found evidence that some clinicians are more 'expert' prognosticators than others. However, the heuristics that these clinicians use to help them make their judgments are largely unknown. Understanding and defining the heuristics may allow us to develop training programmes to enable novice clinicians to become better at prognosticating.

**Abstract number:** P1-485  
**Abstract type:** Poster

## The Development and Validation of a Standardised Transfersheet for Care Transitions between Residential and Acute Care Settings in Leuven, Belgium

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**Background:** When elderly patients are being transferred from a residential to an acute care setting, information regarding their health care can be lost. Also, over the past years, the concept of advance care planning (ACP) has been given a more prominent place in the care for the elderly. However, it remains a challenge to communicate the results achieved by the process of ACP when patients are transferred between health care settings. Developing a sound method for transferring information is a key element in the care for the elderly patient.

**Objectives:** In collaboration with the residential and acute care settings in Leuven, Belgium this study aimed to develop a validated, standardised transfersheet.

**Methods:** After a literature search a topic list was generated containing items that could be considered as essential information during transitional care. This topic list was used in a Delphi-procedure in which 16 experts from both the acute and the residential care settings participated. A transfersheet was developed and then evaluated for content validity by an expert-panel ( $n=9$ ) from both care settings. Face validity was assessed by two nurses and two doctors, randomly selected from the above settings.

**Results:** 11 nursing homes, one university hospital and one regional hospital participated in the study. 16 experts selected a total of 44 essential items including information regarding the pre-morbid cognitive and functional status of the patient, and information regarding the results of the ACP-process. All 44 subthemes in the transfersheet showed excellent content validity. The scale content validity universal agreement (S CVI<sub>UA</sub>) for the entire transfer-sheet was 0.68. The average scale content validity (S CVI<sub>avg</sub>) was 0.96.

**Conclusions:** After a second and final Delphi-round a standardised transfersheet containing 8 themes and 50 subthemes was constructed, validated and implemented. The transfersheet focusses strongly on information regarding the results of the ACP-process.



## Palliative care in children and adolescents

Abstract number: P1-486  
Abstract type: Poster

### Characteristics and Prognosis of the Oldest Old in a Community Hospital and Seen by a Palliative Care Consultation Team (PCCT)

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The Oldest Old is the most rapidly growing geriatric population internationally. This rate of growth will quadruple by 2050. Ten additional years of life is anticipated upon reaching 85. Multiple chronic medical conditions, debility, frailty and geriatric syndromes impact on quality of life and survival.

South Nassau Communities Hospital (SNCH) is a 400+ bed facility with a comprehensive cancer center, cardiovascular institute and 26 critical care beds. SNCH has a medical school affiliation and training programs in family medicine and surgery.

There is a mobile PCCT with a physician, nurse practitioner and social worker each trained and certified in palliative care. Pastoral care and other ancillary services are provided by SNCH. From March 03rd-April 15th 2014, 56 patients were evaluated and 52 of the 56 were assessed for survival at 3 months. The following characteristics were discovered:

- 1) average age: 88;
- 2) female/male 0.9;
- 3) referral source, medicine 75%, critical care 22% and ED 3%;
- 4) reason for referral, goals of care 79%, imminently dying 11%, withdrawal of life support 5% and symptom management, 5%;
- 5) primary illness, cardiac 30%, pulmonary 22%, sepsis 20%, cancer 13%, renal 9% and neurologic 6%;
- 6) avg KPS 20%;
- 7) avg # of co morbidities 4.7;
- 8) 84% incapable of making medical decisions;
- 9) 83% had died by 3 months, 43% during initial hospitalisation, 30% in a hospice facility and 27% in other sites; 17% were alive at 3 months, 56% with homecare hospice, 33% in long term care and 11% at home with no services.

The oldest old is an extremely vulnerable group with a high mortality rate, a diverse variety of life threatening illnesses, profound debility and are commonly incapacitated.

We plan to develop a study providing comprehensive palliative care and geriatric assessments to all oldest old admitted to SNCH and provide education for physicians and nurses with the goal of improving the quality of life and secure a safe and attended death.

Abstract number: P1-487  
Abstract type: Poster

### Developing a Website for Parents and Carers of Children and Young People with Palliative Care Needs: Lessons from the Island of Ireland

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**Background:** Meeting the information needs of parents and guardians of children with palliative care needs is an integral aspect of planning and providing care for that child at home, in a hospital or in a hospice. Providing this information digitally on one website location will reduce the burden on parents trying to navigate the internet and multiple sources of information, which may not be appropriate or relevant.

**Methods:** Drawing on the skills and expertise of a range of stakeholders, a working group was established, which represented service providers, charities and advocacy groups, and most importantly parents of children with palliative care needs. The purpose of this group was to design and develop a website to provide information and guidance to parents and guardians of children and young people with palliative care needs. The website, whilst providing information also acts to filter and direct the user to the most relevant sources of further information.

**Results:** It is anticipated that this resource will assist with meeting the information needs of parents and guardians of children with palliative care needs, in one place with key signposts to relevant information sources. It will also be a resource that health and social care professionals caring for children and young people with palliative care needs, can direct parents to, in order to avoid overloading them with information.

**Conclusion:** This website has the potential to become an integral element in meeting the information needs of parents and guardians of children with palliative care needs and is an example of an innovative and collaborative project across the island of Ireland, which could be translated across other jurisdictions.

Abstract number: P1-488  
Abstract type: Poster

### Are Dogs Really a Child's Best Friend?

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**Background:** More than 40,000 children undergo cancer treatment each day. In the United States, more than 13,500 children are newly diagnosed each year. Although survival rates have improved greatly, the lingering psychological and behavioral effects may negatively impact cancer survivors and their families. Quality of life for childhood cancer patients and their families remains a concern.

**Aims:** This longitudinal study examines 1) the physiological and psychological impact of therapy dogs on children with cancer and their parents, and 2) the impact of animal-assisted intervention (AAI) sessions on participating therapy dogs.

**Methods:** Baseline data were collected from children newly diagnosed with cancer (N=8), mothers (N=8), fathers (N=8), therapy dogs (N=3) and owners (N=3). Families were randomised to usual care or intervention groups. Each intervention consisted of approximately 15 minute AAI sessions at the start of weekly clinic visits. Researchers collected physiologic data (pulse and B/P and cortisol level of dog's saliva), psychological data (anxiety, quality of life, inventory of difficult events for parents), and video-recordings at each AAI session for 16 time points across 4 months.

**Results:** Changes in stress, anxiety, and quality of life among children and their parents over time will be analysed to document preliminary effects of AAI. Activities of dog and child during each intervention will be summarised.

**Conclusion:** This study, funded by the American Humane Association, contributes to the state of science on palliative care. Rigorous data from the randomised trial of the physiological, psychosocial and/or behavioral effects of AAI for children with cancer, their parents, and therapy dogs increases our understanding of the benefits (or detriments) of AAI. After analysis from multiple sites is complete, the study will inform the optimisation of future research and best practices.

Abstract number: P1-489  
Abstract type: Poster

### Exploring Invitation and Recruitment Practices in Research with Children and Young People with Life Limiting Conditions (LLC) or Life Threatening Illnesses (LTI) and their Families - A Systematic Review

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**Background:** Children and young people with LLCs or LTIs are a vulnerable, difficult to treat population. Research is needed to understand how the care, treatment and management of these patients and their families can be improved. Barriers to research include difficulties with securing the support of ethics committees, limited access to children of all ages and their families and the perceived potential burden on all participants. Recruitment to studies in this population is generally slow and delayed.

**Aims:** To provide an overview of current invitation and recruitment practices and influencing factors in recently published research with children and young people with life limiting conditions and life threatening illnesses and their families. We focus on how practices impact recruitment and retention rates.

**Methods:** MEDLINE, PsychINFO, Social Sciences Citation index, Web of Science and SCOPUS were searched to identify original research articles recruiting in this population, published within the last 5 years. Forward and backward citation searches of included studies will be conducted. Studies will be critiqued, assessed for quality, and data extracted on key aspects of recruitment, including how potential participants are approached and what barriers were identified by authors. All key processes will be completed by two reviewers. A meta-analysis exploring the effectiveness of different invitation and recruitment strategies will be conducted and, if data permit, regression analysis will explore factors associated with higher levels of recruitment.

**Results:** The search identified 6,024 articles. We shall present and analyse the type and scope of research in this population and the completeness of the reporting of invitation and recruitment practices.

**Discussion:** Uneven invitation and recruitment practices may lead to sample bias and limit the meaningfulness of findings. Our results will inform the design and reporting of future research in this population.

**Abstract number:** P1-490

**Abstract type:** Poster

## Reaching out to Children and their Families by Offering them Continuity of Care

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**Background:** It is widely accepted that high quality care comes underpinned by accessibility and continuity of care. Understanding and defining Continuity of Care remains a challenge.

**Aim:** To establish the minimum and necessary conditions to offer integrated and fully coordinated palliative care provision care while ensuring children and family transit care levels without solution of continuity.

**Methodology:** Retrospective study to analyze data collected in our group's database first 6 years.

**Results:** The interdisciplinary team offered Specialist Pediatric Palliative Care (SPPC) to 392 children with life threatening conditions in all levels of care in 6 years. 229 (58,4%) of them died during this time, 145 (63,3%) at home and 84 (36,7%) in hospital, 7 (3%) of which were unexpected deaths; 2 (0,9%) died in Accident and Emergency and 8 (3,5%) died during a symptom control admission. All were under the care of the regional Specialist Paediatric Palliative Care Team (SPPCT). 8149 home visits were required, of which 887 (11%) were undertaken out of hours and weekends and public holidays. 355 visits by the SPPCT offered bereavement interventions from medical, nurse, psychologist and social worker, visit to tanatary attendance all the way to ongoing bereavement follow-up.

**Discussion:** Home care and dying for children whose families want and can provide it, is a first class Continuity of PPC Quality Indicator. The change in paradigm brought about in our setting came about because of

1. 24 hour interdisciplinary SPPCT, 365 day a year availability
2. Visiting as requested and in emergency is key to avoid unnecessary admissions and hospital or A&E dying
3. Making all services that might be needed available through the SPPCT.
4. Bereavement being included in continuity of care

**Abstract number:** P1-491

**Abstract type:** Poster

## "Sleep Tight": Developing a Service to Support Children with Cancer to Die at Home

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**Background:** The Sleep Tight project was developed following an approach to the children's hospice from a bereaved parent. The parent had set up a charity in memory of his daughter who died from cancer. He was keen to help the children's hospice to develop a home night sitting service for children and young people (CYP) with cancer who were approaching end of life (EOL). The service would provide benefit to a patient group who have historically not accessed children's hospice services.

**Aims:** The project aims were to increase:

the number of episodes of care at end of life care delivered in the home  
the number of referrals from the Paediatric Oncology Outreach Nurse Specialist's (POONS) to the children's hospice

**Approach:** A project group was developed and included representation from the POONS team. The project was initially piloted in one geographical area.

To ensure adequate staffing to provide the service the hospice added to their professional team by recruiting nurses from the oncology ward to their bank staff. Induction and training was provided for all staff involved in the project to ensure they had the appropriate skills, knowledge and competence to deliver this care in the home. The training covered EOL symptom management in the home, difficult conversations, boundaries and documentation. The POONS were involved in delivering the induction.

**Results:** The project has enabled the hospice and POONS team to develop a stronger working partnership. More children have been able to die at home with the support of the project and with the collaboration of the two services. Early findings show a steady increase in the number of referrals from the POONS. Although the numbers are small, referrals have increased from 2 referrals in 2012 to 13 in 2014 and deaths at home from 0 to 4.

**Conclusion:** Building a stronger partnership between hospice and oncology teams has enabled a more effective support of children, and of families' choice for them to be cared for and die at home.

**Abstract number:** P1-492

**Abstract type:** Poster

## Establishment of Palliative Care System for Children in Ukraine. Call of the Times

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The system of palliative care for children is imperfect in Ukraine: care is provided in health care facilities according to disease profile of the child and by doctors who do not have sufficient skills and conditions. Outpatient care is provided by GPs, who are not specially trained in counseling patients and their families in palliative care. A significant part of care is provided in residential care facility. However, they do not have specially trained medical staff for palliative care for children.

There are 168,000 disabled children under the age of 18, or 2.2% of all children in Ukraine. Annually 8,000 of them, children with serious illnesses or 0.1% of the child population, need palliative care. Major children disability causes are congenital abnormalities and neurological diseases; which compose a circle of customers of palliative care. Annually, about 300 children die from cancer, about 700 from other chronic diseases.

To provide appropriate assistance to such children Palliative Care Center is created on the basis of a Multidisciplinary Intensive Care Hospital for Children. Center comprises of the inpatient unit for 6-12 beds, day hospital for 3 beds and outpatient mobile team for palliative care. The center provides medical staff with conditions for palliative care training in the region.

The main principle of activity is cross-sectoral approach and team work with the involvement of volunteers to alleviate the suffering of young patients and their families. Thus, the establishment of regional palliative care centers for children in Ukraine is caused by morbidity patterns, disability and mortality. Overall, 0.1% of children in Ukraine are in need of palliative care, primarily outpatient.

**Abstract number:** P1-493

**Abstract type:** Poster

## Necessity of Differentiation between Children with Oncological and Non-oncological Conditions

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**Background:** In Switzerland 3'689 children were affected by a life-limiting illness in 2011 (BFS, 2013). Two hundred forty of them died in the same year. The leading causes of death were malformations, leukaemia and neurological diseases. In a tertiary pediatric hospital 20 children die every year, only one of them due to cancer (Greiner, 2014). According to the classification *Together for Short Lives* (Widdas, 2013), children with life-limiting conditions can be attributed to diagnosis group three (progressive conditions without curative possibilities) and four (irreversible, non-progressive conditions with risk of complication and premature death). These Children suffer from various complex problems (Bergsträsser, 2010) which demands in intensiv medical care.

**Research question:** This study investigated how health professionals assess the importance of palliative care in children with non-oncological conditions. Additionally, it was examined which structural, institutional and staffing conditions are necessary to meet the high complexity of care for the affected children and to further develop palliative care.

**Methods:** Eleven guideline-based interviews were performed and evaluated using qualitative content analysis.

**Results:** The analysis revealed the necessity to differentiate between children with oncological and non-oncological conditions in order to sensitize for individual needs of tailored support for affected families to ensure quality of life.

**Discussion:** The study indicates an ongoing professionalization of pediatric palliative care in Switzerland. However, cantons and institutions are requested to implement the concept of the Federation with the aim to establish the required structures and to provide resources (BAG, 2012). For health professionals, specific further training on all educational levels is necessary. Additionally, a common understanding of palliative care provides the basis for networking and cooperation in multidisciplinary Teams.

Abstract number: P1-494  
Abstract type: Poster

**Understanding the Life Issues of Young Adults with Life-limiting Conditions, and the Impact on their Parents, Siblings and Professionals: A Systematic Literature Review**

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**Objective:** This review examined the extent to which the life issues of young adults with life-limiting conditions, and those closely involved with them, have been addressed in the literature.

**Methods:** We conducted a systematic search of five databases for papers published since 2000, which examined the life issues of young adults with life-limiting conditions, either from their own perspective, or from the perspective of those closely involved with them.

**Results:** Nineteen papers were included in the review. There were few studies that examined the unique views of young adults with life limiting conditions, as potentially different from younger children, as they transition to adulthood. There was also a scarcity of studies that facilitated the inclusion of young adults with communication support needs, or included the perspectives of people closely involved with them. Longitudinal studies were also rare.

**Conclusion:** Further research with a specific focus on young adults with a broad range of life-limiting conditions, and those closely involved with them, would enhance understanding of their unique situation as they transition to adulthood. Opportunities to engage with young adults over a period of time would also be beneficial, to fully comprehend their issues as they evolve.

Abstract number: P1-495  
Abstract type: Poster

**Caring for a Child after Death in UK Children'S Hospices: Assessing the Use of 'Cool Rooms'**

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**Background:** UK children's hospices offer bereavement services including caring for children after death using cool rooms/cooling equipment. Current literature offers limited evidence about this practice.

**Aim:** Using a national study to assess the practice of using cool rooms.

**Methods:** An online survey was sent to senior staff in all UK children's hospice services. Questions related to availability of cool rooms/cooling equipment; knowledge of equipment; staff training; data regarding service users over a 3-year period.

**Results:** 23 services replied - 49% response rate; respondents being senior nursing or bereavement care staff. 91% offer this service using a cool room. 66% accept new referrals after death for children not previously known to the hospice. Physical care of the child's body, including final dressing and moving into coffin, is carried out by 83 - 100% of services. Packing the body, if required, is carried out by 61%; no services offer embalming at the hospice. Knowledge regarding temperature of environments/equipment varies: 30% did not report these temperatures; 13% reported temperatures outside published guidelines. 17% reported specific training in caring for a child after death is not offered. A formal competency is available in 40% of services; 35% offer training at induction. Only one service noted mandatory training. Specific data regarding numbers cared for and length of stay after death, from 26% of respondents, showed that the average length of stay after death was 8-10 days and that the number of children cared for after death had increased by 45% from 2012 to 2013.

**Conclusion:** The study provides detailed findings of the provision of physical care after death, specifically regarding use of cool rooms. A small proportion of respondents provided data to suggest increasing use of the service, and increasing numbers of new referrals after death, suggesting that a wider group of bereaved families were gaining access to this service.

# Poster Sessions

## (Poster Exhibition Set 2)

Pain  
Breathlessness  
Fatigue/weakness/cachexia  
Other symptoms  
Assessment and measurement tools  
Audit and quality improvement  
Basic and translational research  
Bereavement  
Communication  
Development and organisation of services  
Education  
Ethics  
Family and care givers  
International developments  
Medical sociology  
Health services research  
Policy  
Public health and epidemiology  
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Social care and social work  
Psychology and psychiatry  
Research methodology  
Volunteering  
Cancer  
Non-cancer  
Palliative care for older people  
Palliative care in children and adolescents



## Pain

**Abstract number:** P2-001  
**Abstract type:** Poster

### Current Trends in Morphine Consumption in a National Oncology Center

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**Background:** Morphine is one of the more ancient medicines known. It is the strong analgesic of choice according to the WHO recommendations for the treatment of moderate-to-severe cancer pain. The appropriate use of morphine in cancer pain patients has been limited for a variety of reasons. The WHO considers a country's morphine consumption to be an important indicator of progress to improve cancer pain relief.

**Aim:** This study aimed to evaluate the current trends in oral Morphine consumption in our institute.

**Methods:** The oral Morphine consumption in our institute between 2006 and 2012 was retrieved from the medical store records.

**Results:** Morphine consumption during 2006 was 651,500mg, and increased by 24% in 2007, further increased by 15% in 2008, then the consumption decreased in 2009 by 10%, again it increased in the years 2010, 2011 and 2012 by 26% & 5.8% and 2.4% respectively.

**Discussion:** Morphine consumption has been increased in our institute from 2006 to 2012 by about 58.2% indicating a possible improvement in cancer pain management. This was not associated with a significant increase in number of newly diagnosed cancer cases during the same period. We noticed also an increase in the consumption of synthetic analgesic (Fentanyl patch) in our institute by more than 7 folds during the same period from 2006 to 2012.

**Abstract number:** P2-002  
**Abstract type:** Poster

### Myths in Cancer Patients about the Use of Morphine in a Third Level Hospital

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**Objectives:** The myths related to opioids specifically morphine, which is a drug of choice for cancer pain, has been a reason for an ineffective pharmacotherapeutic adherence and poor control of pain. The aim of this study is to know the myths about morphine in cancer patients at the National Cancer Institute (INCan) to design a risk minimisation plan.

**Methods:** A prospective, observational situation analysis was performed and used as an instrument of data collection mixed interview, as it will include open, multiple choice and closed questions that will lead the perspective of the patients and their fear of the use of morphine. The surveys were conducted in different INCan's departments. The questionnaires were applied personally by the initial reading of informed consent pointing out the objectives of the study, voluntary participation and confidentiality of the data collected.

**Results:** From a sample of 172 patients, the results are shown below.

Does morphine...

Cause addiction?

Yes 42% No 46% I don't know 12%

Is exclusively for terminal patients?

Yes 54% No 36% I don't know 10%

Is expensive?

Yes 65% No 6% I don't know 29%

Is the last treatment available for pain?

Yes 32% No 41% I don't know 27%

Would you take morphine treatment for your pain?

Yes 61% No 35% I don't know 4%

About morphine...

What's morphine?

Medicine 28%

Illegal Drug 57%

I don't know 15%

What do you want to know about morphine?

How to use it properly and safe treatment.

**Conclusions:** Patients surveyed have serious prejudices and assume as true the myths about morphine. In coordination of pharmacist and palliative care team, patients would have access to reliable and current information about opioid medications promoting adherence to therapy and decreasing risks associated with these drugs.

**Abstract number:** P2-003  
**Abstract type:** Poster

### Opioid Prescribing in a Teaching Hospital – An Audit

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**Background:** An audit of our hospital's strong opioid prescribing practices against the local prescribing standard (a set of quality statements defining poor opioid prescribing).

**Aims:**

To evaluate current prescribing practices

To identify sources of opioid prescribing errors

To assess whether our hospital's pain guidelines provide adequate guidance to healthcare staff

**Methods:** Prescription charts from 29 adult medical and surgical wards were analysed over a month. Prescription charts that contained a regular strong opioid prescription were included in the study. Once the prescription chart was included in the study regular strong opioid prescriptions and all PRN (as required) opioid prescriptions were reviewed.

'Strong opioid' encompasses all formulations of the following medications: morphine sulphate, diamorphine hydrochloride, oxycodone hydrochloride, fentanyl, alfentanil, hydromorphone hydrochloride, and buprenorphine.

**Results:** 60 prescription charts were included in the study. These prescription charts contained a total of 73 errors which were categorised according to quality statements defining poor opioid prescribing.

**Quality statements: total number of errors categorised by each quality statement**

Two or more different regular strong opioids: 1

Inappropriate dosing interval when on regular strong opioids: 8

Inappropriate PRN dose when on regular strong opioid: 29

Inappropriate route for PRN opioid: 1

Dosing interval longer than 2h for PRN strong opioid: 15

Frequency of PRN dose not specified or wrong: 1

Inappropriate combination of routes for the same opioid: 1

No PRN opioid if on regular strong opioid: 14

Missing information or ambiguous prescription: 3

**Conclusion:** Errors in opioid prescribing persist, particularly in calculating breakthrough (PRN) doses for patients who are on a regular strong opioid. Breakthrough dosing is not currently addressed within our hospital's pain guidelines, and it is recommended that this should be considered in future revisions.

**Abstract number:** P2-004  
**Abstract type:** Poster

### Clinical Hypnosis in Palliative Care: Advanced Techniques for Effectively Relieving Pain and Symptoms

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This work will focus on skill building for those clinicians who work with chronic and/or progressive health conditions and patients whose life feels threatened by medical conditions. The aim of the work is: focus on practical hypnotically approaches and techniques with sound underpinnings based on recent advances in our understanding of pain processing.

**Methods and approach:** Clinical hypnosis in Palliative Care is indicated for patients with any serious illness and who have physical, psychological, social, or spiritual distress. The goals of Clinical Hypnosis in Palliative Care, are the same focused on WHO's guidelines for Palliative Care, and they are:

1) Provides relief from pain and other distressing symptoms;

2) Affirms life and regards dying as a normal process;

3) Intends neither to hasten nor postpone death;

4) Integrates the psychological and spiritual aspects of patient care;

5) Offers a support system to help patients live as actively as possible until death;

6) Offers a support system to help the family cope during the patients illness;

7) Uses a team approach to address the needs of patients and their families;

8) Will enhance quality of life;

9) Is applicable early in the course of illness, in conjunction with other therapies.

Following an introduction to the evaluation of chronic pain, a applicable methodology for building therapeutically strategies will be introduced. Practical exercises will encourage participants to build rapid assessment skills while facilitating planning strategies that utilise hypnotic language. At the end of this workshop, participants will be able to:

a) Effectively assess and differentiate the major types of pain and suffering encountered in advanced illness;

b) Develop cogent hypnotic strategies for symptom control;

c) Rapidly develop techniques that reflect and improve: pain, anxiety and suffering relief; dignity and respect for the patients and their families.

Abstract number: P2-005

Abstract type: Poster

## Rapid Onset Opioid (ROO) Rotation in Breakthrough Cancer Pain (BTcP) Management: A Palliative Cancer Case

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**Background:** ROO<sub>s</sub> are fentanyl citrate drugs for the BTcP management, which have a rapid transmucosal absorption (buccal, nasal or sublingual), OTFC (oral transmucosal fentanyl citrate), FBT (fentanyl buccal tablet), FPNS (fentanyl pectin nasal spray), and rapid analgesic action. These are indicated in the treatment of BTcP in patients taking  $\geq 60$  mg/d of oral morphine or equianalgesic doses during the last week.

**Aim:** To describe a clinical case followed by our palliative home care service on ROO<sub>s</sub> rotation.

**Result:** A patient with metastatic breast cancer, followed by our home service from June 2013 received a background pain (BGP) therapy with TTS fentanyl 150µg/h every 48 h, paracetamol 1g/tid, ibuprofen 600mg/bid; for BTcP: OTFC 1200µg+FBT 200µg 4–5/d. Average daily pain intensity was 8 (NRS 0–10). For neuropathic pain pregabalin 25–150mg/d was added. The BGP improved, NRS < 4 after 30 days. She continued to take the ROO<sub>s</sub> 2–4/d. In October 2013 for worsening pain and presence of emesis, prednisone 25mg/d was added. The pain remained controlled until May 2014 when, for ineffectiveness the FBT dose only was increased to 800µg with no rapid onset (about 60 min). For this reason, BTcP therapy was changed with FPNS 400µg obtained rapid onset and partial pain control after 6 min. and total pain control after 9 min. Light dizziness was reported after 9 min, resolved after 12 min. Nowadays patient has no pain with a very good tolerability.

**Conclusion:** The ROO rotation from OTFC+FBT to FPNS has allowed to obtain an optimal pain control with rapid onset, duration and tolerability. It allows opioid sparing and a lower administration number. The better efficacy of FPNS at lower doses is probably due to the way of drug administration. The analgesic properties of FPNS may allow reduction of the total opioid burden and associated adverse effects, while still providing effective pain relief. Our case show the simplicity in determining the dose titration and managing of FPNS.

Abstract number: P2-006

Abstract type: Poster

## Introducing Alternative Forms of Strong Opioids to Control Chronic Pain in Cancer in Moldova: Believing in Unbelievable

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**Introduction:** Palliative care in Moldova has been growing gradually since 2000 and is a relatively new concept which was introduced into the National Healthcare structure in 2008. In order to control chronic pain in cancer patients there was available only injectable form of strong opioid such as morphine.

**Objectives:** To assess the introduction of oral forms of strong opioids in Moldova for effective cancer chronic pain control.

**Methods:** Review of the annual reports of the Charity Foundation for Public Health "Angelus-Moldova" about administration of strong opioids to control chronic pain in cancer incurable adult patients.

**Results:** In February 2012 oral tablets of extended-release morphine were introduced into the local pharmaceutical market and in March 2014 oral solution of methadone became available as alternative pain killer for effective control of chronic pain in cancer patients with high dosage of injectable morphine.

**Conclusions:** Despite the fact that there are still not enough alternative forms of strong opioids and variation of their dosage, introduction of oral slow release morphine and beginning of the oral methadone administration not only for replacement therapy is a significant step forward in modern control of chronic pain in adult incurable cancer patients in Moldova.

Abstract number: P2-007

Abstract type: Poster

## Use of High Doses of Opioids for Elderly Cancer Patients with Moderate to Severe Cancer Pain: Prospective Observation Study

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**Aims:** Cancer pain can be well controlled by using opioids. However, a lot of cancer patients are still suffering from intractable pain due to underestimation or improper treatment of their pain, particularly in the elderly.

**Methods:** We prospectively observed the use of high dose opioids and adjuvant drugs for pain management in elderly cancer patients. The changes in pain severity (NRS), opioids dosage, parameters associated with quality of life and adverse events of opioids were investigated in outpatient's clinic after 8 weeks. Data from 94 cancer patients aged more than 65 years with high dose opioids (OME $\geq$ 120 mg/day) were collected from 30 hospitals from February 2009 to March 2010.

**Results:** Ninety four patients with moderate to severe pain were followed up for 8 weeks. A total of 92 patients (74.5% received only Oxycontin<sup>®</sup>) were prescribed opioids at the end of the study. Sixty two patients (67.4%) were male and mean age of patients was 70.2 years. Mean pain intensity and opioid dosage (OME) were changed from 5.61 $\pm$ 1.56, 178.86 $\pm$ 76.88 at baseline to 4.02 $\pm$ 2.169 ( $p$ < 0.001), 288.54 $\pm$ 389.09 ( $p$ =0.0025) after 8 weeks. Quality of life consisting of daily activity, ambulation and sleep were significantly improved after 8 weeks ( $p$ < 0.001). Also, pain intensity and the frequency of adverse events by opioid type after 8

weeks were not different.

**Conclusion:** Pain severity and quality of life were improved in elderly cancer patients using opioids.

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Abstract number: P2-008

Abstract type: Poster

## Using PK/PD Model to Optimise Dosing of Morphine in Renal Impaired Patients

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**Background:** A major problem related to morphine is dosing in patients with renal insufficiency, and no guidelines for dose adjustments exist. As a result of decreased renal clearance, accumulation of morphine metabolites (M6G & M3G) can lead to serious adverse effects. In renal failure, morphine use is generally not recommended as accumulation of the metabolites is unpredictable. Case reports in patients with renal insufficiency have shown high and prolonged concentrations of M6G after morphine administration. Furthermore, the high concentrations of accumulated M6G can contribute to morphine analgesia, which again supports dose adjustment in renal insufficiency patients as lower morphine doses might be sufficient for analgesia.

The aim was to simulate the M6G contribution to analgesia after oral administration of morphine in patients with renal insufficiency using a population PK/PD model.

**Methods:** In the simulations, 30 mg morphine was administered orally four times daily to a patient with five degrees of renal insufficiency; 0% (normal renal function), 25%, 50%, 75%, and 95% reduced renal function.

**Results:** In subjects with normal renal function, M6G contributes approx. 27% to the total analgesia after oral administration of morphine at steady state (18.5% response). As renal function declines, M6G contribution to analgesia increases, while morphine analgesia is unaffected. The estimated doses needed to reach the target response of 18.5% as seen in a patient with normal renal function were 28 mg, 24 mg, 17 mg, and 5 mg, for 25%, 50%, 75%, and 95% renal impairment respectively.

**Conclusion:** M6G accumulates after administration of morphine to patients with renal impairments, and analgesia can be obtained with lower doses of morphine compared to patients with normal renal function. Thus, dose should be reduced to avoid side-effects, although the simulations in this review did not account for side-effects and the possible contribution the these due to M3G.

Abstract number: P2-009

Abstract type: Poster

## Is Tolerance to Alfentanil in Continuous Subcutaneous Infusion (CSCI) a Clinical Problem in a Specialist Palliative Care Unit Cohort?

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**Background:** Alfentanil is an opioid analgesic increasingly delivered in palliative care by CSCI where conventional opioids are poorly tolerated, particularly in chronic kidney disease (CKD). There is conflicting literature on whether tolerance to Alfentanil is a clinical problem.

**Aims:** We wished to explore dose changes over time in our cohort of patients receiving Alfentanil.

**Methods:** 18 consecutive patients during February–May 2014 on Alfentanil comprised the cohort. Notes were requested and data extracted retrospectively.

**Results:** Data were available from 17 notes. Average age of patients was 66 years. Of the 17 patients, only 1 had non-malignant disease – CKD. 12 (71%) patients died whilst prescribed Alfentanil. 5 were switched to alternative opioids or continued on Alfentanil therapy at the time of study end. 14 (82%) of the 17 patients were switched to Alfentanil as a result of opioid toxicity. Mean start dose of Alfentanil was 4.17mg per day, with substantial increases over the first week. The mean dose had more than doubled to 8.9 mg after 5 days. 1 patient with CKD had noticeably little dose titration – start dose 0.2 mg increasing to 0.4mg per day after 1 week with no further increases after 19 days of therapy. Mean end dose of Alfentanil was 14.8mg per day. Median duration of treatment with Alfentanil was 13 days.

**Conclusions:** Alfentanil doses were shown to increase substantially, particularly in the first week of use, indicating that tolerance does occur in some patients. There appear to be some individuals in whom tolerance does not occur. Alfentanil is predominantly used for patients who are nearing end of life. Given the propensity to develop tolerance, this is an appropriate niche for its use, particularly in CKD.

**Abstract number:** P2-010  
**Abstract type:** Poster

## German Nursing Guideline: Nurse-led Pain Management of Chronic Pain

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**Aims:** For the management of chronic pain no nursing guideline existed in Germany. This leads to poor quality of life and several adverse events (physical burden, sleep disturbance, depression, anxiety) and is a tremendous financial burden for the health service (longer hospital stays, higher care dependency, disability). Nurses had no scope of action according to chronic pain patients.

The German Network of Quality Improvement in Nursing released in 2014 the nursing guideline: pain management of chronic pain. The guideline aims to improve the pain management of patients with chronic cancer and non-cancer pain of all age-groups. It is feasible for all health care settings.

**Approach:** A literature review identified guidelines for chronic pain. After the rating (DIMDI criteria) 28 guidelines could be included in the guideline development. An expert group of ten nurse researchers and practical nurses developed the guideline on the base of the existing guidelines and their expertise. The guideline was adopted in a consensus conference with 600 nurses.

**Results:** The guideline defines the outcomes of the pain management: to enhance or sustain the quality of life and functional status, to reduce the pain to a stable and individual acceptable pain level, social participation and the prevention of crisis.

The guideline is structured in five intervention categories:

1. a criteria-led pain assessment
2. the development of treatment plan in the multidisciplinary team
3. patient education to empower the patient and enhance self management strategies
4. pharmaceutical and non-pharmaceutical pain management and prevention of adverse effects
5. documentation and re-evaluation of the defined outcomes

**Conclusion:** With support of this evidence-based guideline the authors and the quality network intend to improve the pain management of patients with chronic pain. The mandatory implementation of pain nurses will help to achieve this health outcome in Germany.

**Abstract number:** P2-011  
**Abstract type:** Poster

## Is Pain Control Enough to Achieve Quality of Life?

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**Background:** The quality of life in patients with cancer depends not only on good somatic symptoms control. The role of psychosocial support is being minimised or neglected. Such attitudes can also be found in the field of palliative care. Aim of the study The study aimed to verify if pain and other symptoms control is enough to secure good quality of life (QoL).

**Materials and methods:** 55 in-patients (22 men, 33 women, 44–82 years, M=67), treated in three hospices, were examined. Pain was measured using The *Numeric Rating Scale* (NRS) with 3 questions: pain level now, average last week, maximum last week. Symptoms severity and quality of life were measured using Quality of Life Questionnaire – Palliative (QLQ-C15-PAL). Patient's needs, satisfaction and deprivation were measured using self-developed Patients Expectation and Satisfaction Questionnaire (PESQ). Results were analysed statistically.

**Results:** Both current and last week average pain in the study had a mean score below 3 (respectively 2,69 and 2,78) and the maximum pain last week averaged to 5.24. This suggests good pain control with episodes of medium to severe pain. The average perceived (subjective) QoL was 37,9% and was even lower than quality of life resulting from the intensity of symptoms 40,6%. It was also observed that the average and current pain did not correlate with perceived QoL and correlated with symptoms QoL. Only maximum pain showed significant negative correlation with perceived QoL. PESQ results showed that the most important needs and expectations were related to psychological and social areas and were not perceived as satisfied enough. Satisfaction of psycho-social needs correlated positively with QoL.

**Conclusion:** The results confirm the important role of psychological and social support in achieving high quality of life in palliative patients. We noticed that patients can developed adaptive mechanisms to pain NRS < 7. Good symptoms control is not enough to complete palliative care.

**Abstract number:** P2-012  
**Abstract type:** Poster

## There's a Place for it! Introducing Nasal Fentanyl in a Regional Cancer Centre

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**Background:** Fentanyl is a strong opioid delivered by the nasal route, originally developed for patients with breakthrough pain. The titration phase differs from other opioids used for breakthrough analgesia. Both patients and staff require education before starting use and during the first days.

A regional cancer centre has explored which patients benefit from early introduction of the drug and how to ensure that staff/patients are confident in using the drug safely.

**Aims:** To assess the indications for use of nasal fentanyl in a regional cancer centre.

To review the effectiveness of dose titration and the side-effects experienced by patients.

To explore the challenges faced by patients and staff in using the drug effectively.

**Method:** A retrospective review of the case notes of patients prescribed nasal fentanyl in the centre over an 18 month period between Jan 2013 and July 2014.

The data collected included demographics, indication for use, titration schedule, final dose, side-effects, and discharge arrangements.

**Results:** 14 patients were prescribed nasal fentanyl over an 18 month period.

100% were referred to the hospital specialist palliative care team.

98% of patients were taking 60 mg morphine daily, or equivalent, when fentanyl titration started.

The most frequently used maintenance dose of nasal fentanyl was 100mcg (range 100–800mcg).

57% patients were discharged home/other care settings on nasal fentanyl.

The drug was used in the dying phase for 1 patient.

Detailed breakdown of Pecent use will be available in the final report.

Challenges for staff included becoming familiar with the titration regimen.

**Conclusion:** Nasal fentanyl is a useful addition to the range of treatment options for patients with cancer pain. Education is vital for titration due to potential confusion with the titration of other fast acting fentanyl preparations. Education and availability of resource material for both staff and patients is essential.

**Abstract number:** P2-013  
**Abstract type:** Poster

## L-Methadone Intravenously Solved Opioid Induced Hyperalgesia in a Child

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**Background:** Children in severe pain through progressive or disseminated oncologic disease are very often in need for rather high dosages of opioids in comparison to adults. Mostly they show good tolerance and rather no relevant side-effects. Increasing general clinical knowledge about neuropathic syndroms e.g. allodynia, allows to diagnose opioid-induced hyperalgesia nowadays more often. If opioid rotation within standard-opioids is not effective in sense of controlling side-effects and pain, rotation to intravenous methadone as an ultima ratio was described in only one single case report in children so far.

**Case report:** We report about an 7 year old girl (body weight 20 kg) suffering from disseminated ewing-tumor and insufficient pain relief despite intravenous opioid therapy (PCA). At this stage oral medication intake was not more applicable due to disturbed gastrointestinal passage. In the course opioid dosage had to be escalated successively due to increasing painlevels, up to an cumulative daily dosage of 10,000 mg oral morphine aequivalent (500 mg/kg body weight), in combination with multiple co-analgesics. Instead of further pain control the girl showed ongoing pain at the primary tumor location (left lower limb) and developed furthermore a pronounced hyperalgesia and allodynia. At the end even the breath from talking, reaching her skin, made her cry from pain. After rotating her to L-Methadone with abrupt discontinuation of morphine let to sufficient pain relief and disappearance of hyperalgesia. L-Methadone was started with basal rate 2 mg/h, bolus 3 mg, lock-out time 20 min and escalated up to an maximum of 15 mg/h, effectively around 20 mg/kg body weight/d.

**Conclusion:** L-Methadone should be taken into account for treatment of opioid induced hyperalgesia in children as co-occurrence of neuropathic side-effects under high dosage of opioids.

Abstract number: P2-014  
Abstract type: Poster

# **A Comparison of Analgesic Effectiveness between Transdermal Fentanyl Patches Developed in Japan, Requiring Replacement Every 24 Hours, and Conventional Transdermal Fentanyl Patches Requiring Replacement Every 72 Hours**

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**Background:** In Japan, transdermal fentanyl patches (TDF) requiring replacement every 24 hours (Fentos® Tape, FT) have been commercially available since 2010. FT is characterised by less variability in steady-state blood fentanyl concentrations as compared with conventional TDF requiring replacement every 72 hours (Durotep® MT Patch, DT).

**Methods:** The medical records of inpatients who used TDF from July 2008 through December 2013 at Kitasato University East Hospital were reviewed. The number of rescue doses of analgesics used from day 4 to the final day of continuous treatment with the same dose was surveyed. To be eligible the patient had to have received the same dose of TDF for at least 12 days. Patients were excluded if pain was poorly controlled and rescue doses of analgesics were received 4 or more times per day for at least 1 day from days 4 to 6 of treatment.

## **1. Primary endpoint**

The number of rescue doses used per day during the study period was compared between FT and DP.

## **2. Secondary endpoint**

For DP, the number of rescue doses used per 24-hour interval during 72 hours after the application of a single patch DP was compared.

**Results:** During the study period, FT was applied to 120 patients, and DP was applied to 184 patients.

- Twenty-seven patients in the FT group and 48 patients in the DP group were included in the analysis of the primary endpoint. The number of rescue doses used per day was significantly smaller in the FT group (median, 0.1; range, 0–1.9) than in the DP group (0.7; 0–3.0) ( $p=0.041$ ).
- Thirty-two patients in the DP group were included in analysis. The median number of rescue doses used per 24-hour interval after application was 0.6 (0–2.5) on day 1 (12–36 h), 0.5 (0–3.0) on day 2 (36–60 h), and 1.0 (0–3.5) on day 3 (58–70 h plus 0–12 h). The differences were significant between day 1 and day 3 ( $p=0.002$ ) and between day 2 and day 3 ( $p=0.008$ ).

**Conclusions:** At stable blood drug concentrations, FT provided better pain control than DP.

Abstract number: P2-015  
Abstract type: Poster

# **Tackling the Constipation Problem in Long-term Opioid Analgesia**

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**Background:** Opioids are potent analgesics, but cause opioid-induced constipation (OIC) which affects quality of life and reduces treatment compliance. Many laxatives used to treat OIC mostly affect the colon by a mechanism of action that may be flawed for OIC treatment, as this results from opioid-receptor stimulation that distresses the entire gastrointestinal tract.

Peripherally acting  $\mu$ -opioid receptor antagonist naloxone is a targeted treatment for OIC. Oxycodone/naloxone prolonged release tablets (OXN PR) combine an opioid analgesic (oxycodone) with naloxone. Clinical trials reported that OXN PR improves bowel function without impairing analgesia.

**Aim:** To evaluate and compare the impact of standard laxatives with opioid therapy to OXN PR on OIC and analgesic efficacy during long-term treatment with OXN PR in adults with moderate-to-severe chronic pain.

**Method:** We performed a literature search for reports of bowel function in patients taking opioids and laxatives. We evaluated a study that combined (using pooled analysis) data for analgesia (average pain over last 24 hours' scale) and bowel function (Bowel Function Index (BFI)) in 474 patients receiving OXN PR over 52 weeks.

**Results:** Opioids cause severe OIC and laxatives don't solve the problem. The pooled analysis showed improvement in bowel function was continued during 1 year of treatment and analgesic efficacy was maintained; furthermore less than 10% of patients took laxatives on a regular basis.

A clinically meaningful, statistically significant improvement in bowel function (average BFI score reduction  $\geq 12$ ) was observed in patients who switched from Oxy PR to OXN PR: within a week, the mean (SD) BFI score decreased from 44.3 (28.1) to 26.5 (24.4).

**Conclusion:** During pain therapy OIC is a serious problem inadequately addressed by laxatives. OXN PR can ameliorate OIC, avoiding the need for regular laxative use, while effectively treating chronic non-cancer pain in the long term.

**Funded:** Mundipharma

Abstract number: P2-016  
Abstract type: Poster

# **Revealing the Extent of Cognitive Impairment in Patients who Are Prescribed Opioids**

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**Background:** Previous studies have shown patients on opioids have impaired cognitive function. This has been demonstrated particularly at initiation or titration of opioid. Studies have often relied on the mini-mental state examination (MMSE) or more specialised neuropsychological tests.

**Aim:** The study aimed to assess cognitive function using the Addenbrooke's Cognitive Examination-revised (ACE-R) in patients who were prescribed opioids and to compare impact on cognitive function between patient groups.

**Method:** Patients who were prescribed opioids for cancer or non-cancer pain and substance misuse were recruited, as were patients with non-cancer pain who were not on opioids. Opioid history was recorded. Patients completed the ACE-R, hospital anxiety and depression scale and brief pain inventory. The ACE-R provides a score out of 100 from which the MMSE score is extracted. Information is provided on five domains of cognitive function. Assessments were completed every six to eight weeks. Most patients completed two assessments; some cancer patients completed three.

**Results:** 170 patients were recruited; 89 had cancer pain. Using the MMSE 45 patients (26.5% of all patients) had definite or possible cognitive impairment; this increased to 65 patients (38.2%) when using ACE-R. Using the MMSE 27 patients (30.3%) of cancer patients had cognitive impairment; this increased to 42 patients (47.2% of cancer patients) when the ACE-R was used. The mismatch between tests was statistically significant in all patient groups. Attention, memory, fluency and visuospatial abilities were impaired. Language was relatively preserved. No correlation was found with pain, anxiety or depression. Cognitive impairment (CI) persisted over time.

**Discussion:** Using the ACE-R reveals significantly more CI in patients on opioids than the MMSE. The ACE-R revealed the domain of cognitive function affected. Although it is likely to be multifactorial, opioids will be responsible for some of the impairment.

Abstract number: P2-017  
Abstract type: Poster

# **Nursing Perceptions about Managing Pain Medications in Long Term Care**

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**Background:** Pain management for older adults living in long term care (LTC) has been recognised as a problem worldwide. Despite the high rates of pain experienced by residents in LTC, pain continues to be under-assessed and under-treated. Untreated pain can lead to numerous negative outcomes such as decreased functional abilities, depression, impaired mobility, sleep disturbances, anxiety, and dissatisfaction with life.

**Aims:** The purpose of this study was to explore nurses' perceptions of their current practices related to administering pain medications to LTC residents.

**Methods:** A cross-sectional survey design was used including both quantitative and open-ended questions. Data was collected from 165 nurses (59% response rate) at nine LTC homes in southern Ontario, Canada.

**Results:** The majority (85%) felt that the medication administration system was adequate to help them manage residents' pain and 98% felt comfortable administering narcotics. In deciding to administer a narcotic, nurses were influenced by pain assessments; physician orders; diagnosis; past history; effectiveness of non-narcotics; and fear of making dosage miscalculations or developing additions. Finally, most nurses stated that they trusted the physicians and pharmacists to ensure orders were safe.

**Conclusions:** These findings highlight nurses' perceptions to managing pain medications in LTC and related areas where continuing education initiatives for nurses are needed.

Abstract number: P2-018  
Abstract type: Poster

# **Usefulness of Percutaneous Neurolytic Celiac Plexus Block with IVR-CT System for Pain due to Pancreatic Cancer**

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**Background:** Percutaneous neurolytic celiac plexus block (PNCBP) is an excellent treatment option for patients with intractable abdominal pain due to pancreatic cancer. Some techniques have been conducted clinically including fluoroscopy- or computed tomography (CT) – guided percutaneous approaches. However, each technique has both good and bad points.

**Aims:** The purpose of this study was to evaluate the therapeutic value of IVR-CT (sliding CT scanner system with interventional radiology features) on PNCBP for abdominal pain due to pancreatic cancer.

**Methods:** Eighteen patients were enrolled in this study and allocated to three groups; patients underwent PNCBP with IVR-CT system (IVR-CT group : n=6), with fluoroscopy-guided (FLU group : n=6) and with CT-guided (CT group : n=6). Operative time and required volume of 99% ethyl alcohol were recorded.

**Results:** All patients reported an abdominal score of 2 to 3 out of 10 on the Numeric Rating Scale (NRS) on the next day of PNCBP. Although a trend towards shorter operation time was seen in IVR-CT group, this did not reach a significant difference. Required volume of ethyl alcohol for PNCBP was smaller significantly in IVR-CT group than in other two groups.

**Conclusion:** In addition to fluoroscopic procedure, combined management workup with sliding CT could be associated with an improved outcome. Therefore, applying IVR-CT system to PNCBP might be useful for treatment of abdominal pain due to pancreatic cancer.



**Abstract number:** P2-019

**Abstract type:** Poster

## **Analgesic Effect and Safety of Mixed Solution of Oxycodone, Ketamine and Lidocaine for Cancer Pain**

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**Background:** We usually administrate mixed solution of oxycodone, ketamine, lidocaine intravenously for fast analgesics titration for cancer pain, and got good pain relief safely. Ketamine and lidocaine might be effective for cancer pain and postoperative pain as co-analgesic in addition to opioids.

**Aims:** We measured the plasma concentration of these drugs and investigated the correlation between the plasma concentration of these drugs and analgesic effect, and safety of these drugs.

**Methods:** This study design was a prospective, non-randomised, non-blinded study, and was performed between March 2013 and December 2013. Five patients were enrolled. All patients had cancer pain and didn't use any opioid analgesics. We administrated oxycodone, ketamine, lidocaine mixed solution intravenously by an electrical patient-controlled analgesia (PCA) pump with basal infusion. Blood samples were T1: control, T2: patients felt pain relieved, T3: an hour after T2, and T4: tomorrow morning. Plasma concentration of study drugs were measured. Pain intensity and adverse effect were evaluated at all sampling time.

**Results:** All patients felt pain relieve at T2. Mean minimum effective concentration (MEC) of oxycodone was 12.65 (8.74–20.8) ng/ml. That of ketamine and lidocaine were 2.31 (1.45–4.26) ng/ml and 168(109–222) ng/ml. No patients experienced severe respiratory depression and decrease blood pressure. At T3 and T4, the plasma concentration of study drugs were almost within twice of MEC. The correlation between pain intensity/other adverse effects and plasma concentrations of study drugs were not clearly.

**Conclusion / Discussion:** We measured the plasma concentration of study drugs at T1–T4. We succeeded fast titration of opioids. Ketamine and lidocaine adding oxycodone might be effective for cancer pain. With basal infusion, respiratory depression by opioid did not occur. Basal infusion of oxycodone, ketamine, lidocaine might be safety and decrease opioid assumption. Further study is needed.

**Abstract number:** P2-020

**Abstract type:** Poster

## **Pain Control Management after Patients Become Unable to Take Methadone Orally in the End of Life**

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**Background:** In Japan, oral administration of methadone for patients with cancer pain was approved in March 2013. However, as methadone can only be administered orally in Japan, it is unclear how to treat pain when patients become unable to take orally due to progression of the disease.

**Aims:** To assess end-of-life management retrospectively, especially pain control management, after patients became unable to take methadone orally.

**Methods:** Twenty-eight patients with cancer pain undergoing treatment with oral methadone died at a palliative care unit in Japan between April 2013 and September 2014. All patients died of cancer and became unable to swallow before death. We assessed pain control approaches after the patients became unable to take methadone orally.

**Results:** The medication was not switched to other opioids due to the absence of pain in seven of the 28 patients, and these patients died within one day after the final methadone administration. The drug was switched to another opioid because of pain in 21 patients: one patient was treated with transdermal fentanyl, two were treated with subcutaneous oxycodone, and 18 were treated with subcutaneous morphine. Of these 21 patients, 11 patients died within one week, and 10 patients survived for one week or longer after switching to another opioid. In seven of these 10 patients, excluding three patients in whom pain could not be evaluated, the final oral methadone dosage was 20–150 mg/day, and the oral morphine equivalent dose of opioids used on the 7<sup>th</sup> day, when methadone would have been mostly eliminated from the circulation, was 120–3,400 mg/day, with a conversion rate of 6.1.

**Conclusion:** Pain could be managed by switching to other opioids, even when patients became unable to ingest methadone. Due to the long half-life of methadone, when pain is absent in the end of life, switching to other opioids may be not always necessary even when oral methadone medication becomes impossible.

**Abstract number:** P2-021

**Abstract type:** Poster

## **Evaluation of the Optimal Positioning of Subcutaneous Butterfly when Administering Injectable Opioids in Cancer Patients**

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**Introduction:** The growth in number of cancer patients, together with the development of new Palliative Care services in Romania warrant the evaluation of nursing strategies used to enhance the level of comfort of patients who are suffering with advanced cancer.

**Goal:** The main objective of the present study was to evaluate optimal positioning of the subcutaneous (sc) butterfly, in accordance with its resistance in the insertion tissue, the local complications that occur and the evaluation of the time of resistance at the insertion site (puncture) with the daily frequency of injectable opioid administration.

**Method:** A prospective experimental pilot study was designed and conducted between January and May 2011. Patients admitted at Hospice Casa Sperantei (Brasov, Romania) with moderate or severe cancer pain receiving subcutaneously opioids, over the age of 18, with normal body index ranging from 18.5–22.0, after signing the informed consent, were assigned in a random method to one of the two groups: group 1 butterfly was positioned with the needle's bevel up – this was considered to be the control group as this modality of inserting the needle is considered standard practice; group 2 butterfly was positioned with

the needle's bevel down – experimental group. The drugs used for pain relief were sc Tramadol for moderate pain and sc Morphine for severe pain.

**Results:** Our research supported the hypothesis that the occurrence of local complications comes together with the decrease of sc butterfly resistance in time at the place of insertion and the sc butterfly have a higher rate of resistance in time at the insertion site if the frequency of injectable opioids administration is lower (twice per day). The positioning of the butterflies with the bevel down (experimental group) is associated with a longer resistance in time at the site of insertion and causes less local complications compared to the sc butterflies positioned with the bevel up (control group).

**Abstract number:** P2-022

**Abstract type:** Poster

## **Conceptual and Attitudinal Barriers to the Use of Symptom Measures in the Management of Pain**

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**Introduction:** There are significant challenges in bringing systematic symptom measurement to the palliative care population including both attitudinal and conceptual barriers.

**Objectives:** This paper reviews challenges in palliative medicine i.e. conceptual and attitudinal barriers to the use of symptom measures in pain management.

**Discussion:** Conceptual and attitudinal barriers to the use of health status measures in patient care and clinical trials (1) are likely to be relevant in the palliative care setting. These include skepticism about the validity and importance of self-rated health measures, preferences for physiological outcomes or death rates, unfamiliarity of healthcare providers with the scoring measures, and a paucity of direct comparisons among instruments. Education of health professionals about measurement techniques should be viewed as a priority in efforts aimed at eliminating barriers and improving symptom management. In a survey of physicians providing care for patients with cancer, 76% stated that the single most important barrier to adequate pain management was poor pain assessment (2). The absence of valid measures for the measurement of many common symptoms represents a major methodological barrier to improving symptom measurement. As a result, many studies have used checklists to measure symptom prevalence without reference to symptom distress and impact.

**Conclusion:** Systematic symptom assessment is a foundation of clinical practice and research. Instruments for measurement of symptoms have been developed and may facilitate this process.

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**Abstract number:** P2-023

**Abstract type:** Poster

## **Potency of the Acetaminophen Injection for Cancer Pains in Japan**

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**Background:** Cancer patients often have decreased physiologies such as liver function and renal function; therefore, it is necessary to use safe and effective analgesics. In Japan, the acetaminophen injection (AI) was approved for use in November 2013. Because administering an acetaminophen in injection form evades metabolic effects, blood level control becomes easier than with conventional oral administration of acetaminophen. Considering that cancer patients often experience decreased deglutition function and metabolic capacity, AI is believed to be suitable for them. However, the history of usage of AI in Japan is still short; there are no reports about its usage in cancer pains.

**Purpose:** To examine whether AI is beneficial for cancer pains in Japan.

**Method:** We retrospectively evaluated cancer patients who were administered AI at a municipal hospital and a university hospital in Japan from November 2013 to September 2014. The patients' backgrounds, doses of AI, pain intensity differences (PID), laboratory test values, combined drugs, and so on, were obtained from their medical records. Pain was on a 4-point scale (none: 0, weak: 1, strong: 2, severe: 3).

**Result:** Improvement by AI were observed in 46 of 58 subjects. The PID was  $1.1 \pm 0.7$  (mean  $\pm$  SD). Among all subjects, analgesic effect appeared in 85% of postoperative patients, and 72% of non-postoperative patients with cancer pains. In the cases of non-postoperative patients with cancer pains, no significant liver damage was identified, moreover, AI sometimes provided analgesic effects when some NSAIDs were ineffective.

**Conclusion:** The current study was performed at early stage, but the findings suggest a potency for AI to be effectively used for cancer pains in Japan. We certainly intend to perform this study in a greater number patients in association with other institutions, which would increase the credibility of our findings.

**Abstract number:** P2-024  
**Abstract type:** Poster

## Tapentadol as an Alternative in Opioid Rotation in Cancer Pain

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**Background:** The prevalence of pain in advanced cancer patients ranges from 70% to 80%. In these patients, opioid rotation is often used when adverse events occur after an good pain control. To ensure an optimal balance between analgesia and side effects, physicians should be aware of all the options available on the market to choose the most suitable alternative.

**Aim:**

To review cases in which there was rotation from a major opioid to Tapentadol. To check the tolerability profile and analgesic efficacy in these patients.

**Methods:** Type of study: Observational, longitudinal and retrospective study. Case series. Site: Fundación Instituto Valenciano de Oncología, Valencia (Spain).

**Study population:** Patients admitted at the Palliative Home-Care Unit and outpatients who came for consultation to the Pain Management Unit in the Medical Oncology Department. Variables: sociodemographic, Verbal Analogic Scale (VAS), clinical records of side effects.

**Results:** Thirteen patients were identified who rotated from a major opioid (transdermal Fentanyl, oral Morphine, oral Oxycodone, Buprenorphine) to Tapentadol; it was verified that the conversion ratios used were based on non-cancer pain. In 11/13 cases, no side effects that required the drug's withdrawal were recorded. In the other two cases, the reason for withdrawal was vomiting of multifactorial origin, requiring the use of parenteral administration of analgesia and antiemetic medication. Appropriate analgesic control (VAS < 4) was obtained in 9/13 cases.

**Conclusions:**

Tapentadol is a valid option in the treatment of advanced cancer pain.

In the absence of ad hoc studies, its tolerability profile and analgesic potency make it an alternative for opioid rotation in patients with cancer pain.

**Abstract number:** P2-025  
**Abstract type:** Poster

## Diamorphine or Alfentanil for Subcutaneous Use in Hospice In-patients (DASH)? PILOT

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**Background:** There is variability in how patients respond to different opioids. In the United Kingdom standard practice is to use diamorphine as a subcutaneous infusion via syringe driver when patients are unable to take strong opioids orally. Alfentanil is another strong opioid which can be used in this way but its use is often reserved to those with renal impairment where it is believed it may have fewer adverse effects. There are no randomised trials comparing diamorphine and alfentanil in palliative care patients.

**Aims:** To explore the feasibility of a randomised controlled trial of diamorphine versus alfentanil via syringe driver for specialist palliative care patients without severe renal impairment.

**Study design and methods:** Specialist Palliative Care Unit inpatients requiring diamorphine via syringe driver with an estimated prognosis between 1 week and 1 year and an estimated glomerular filtration rate of greater than 40ml/min were approached. After a minimum 24 hours cooling off period those interested were consented and randomised to stay on diamorphine or switch to alfentanil in an open label fashion. An approximate 1:10 conversion was used (alfentanil:diamorphine).

Daily assessments were conducted including the Brief Pain Inventory-Short Form (BPI-SF) and Memorial Delirium Assessment Schedule (MDAS).

**Results:** To date 18 (of a target of 20) have been randomised (9 in each arm). Preliminary results show that that the only statistically significant differences (Mann-Whitney U tests) were with regard to components of the BPI-SF on days 1-5 all favouring diamorphine. There were no differences in MDAS scores.

**Conclusion/discussion:** Some of the differences in pain scores could potentially be due to problems of initial conversion to alfentanil. However, these differences were maintained at Day 5. The data from this study does not support the case for a larger study with the hypothesis that alfentanil might be better for patients without renal impairment.

**Abstract number:** P2-026  
**Abstract type:** Poster

## A Regional Audit Examining the Use of Topical 5% Lidocaine Plasters in Patients with Cancer Related Neuropathic Pain

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**Background:** Neuropathic pain is experienced in one third of cancer patients. Its treatment can be challenging, and it is suggested that neuropathic pain is to blame in half of cancer patients whose pain is inadequately controlled.

Topical 5% lidocaine plasters, although unlicensed for use in cancer related neuropathic pain, present a safe and well tolerated management option. Practice amongst palliative care practitioners seems varied with some local scepticism due to its small and inconclusive evidence base. No work had been performed in our region examining their use in cancer patients with neuropathic pain.

**Aim:** To assess the use of 5% lidocaine plasters in patients known to palliative care services in our region, focussing on patient selection and appropriate prescribing.

**Methods:** Retrospective multi-centre case note audit. Organisations contacted via e-mail with an invitation to participate. Each site was responsible for identifying appropriate case notes and carrying out data collection. Responses submitted via an on-line, electronic data collection form. Data analysis performed centrally by the regional audit department.

**Results:** 35 data collection forms were submitted from 7 organisations. 89% patients had cancer related neuropathic pain. In only 40% cases was the lidocaine plaster prescribed 3<sup>rd</sup> line or later, as per guidelines. In 57% cases the plaster was prescribed to cover the site of described pain and 80% cases trialled the plaster for up to maximum of 4 weeks but only 9% had a pre-planned, time-defined review. In cases where the patient changed care setting, 47% had a documented handover to the receiving team.

**Conclusion:** Overall patient selection seemed appropriate. However, the lidocaine plasters were not always used in accordance with recommended guidelines and this audit has highlighted areas for improvements. Consequent recommendations have been made within the region.

**Abstract number:** P2-027  
**Abstract type:** Poster

## The Role of Intranasal Fentanyl in a Specialist Palliative Care Inpatient Unit – A Retrospective Study

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**Background:** Intranasal Fentanyl (INF) is indicated for the management of breakthrough cancer pain in opioid-tolerant patients already receiving maintenance opioid therapy for chronic cancer pain. **Aim:** To carry out a retrospective study to assess the efficacy of intranasal Fentanyl and indications for its initiation in patients admitted to an inpatient palliative care unit (IPCU) within the UK.

**Method:** A Retrospective study, reviewing the medical notes of patients admitted to an inpatient unit in a 1 year period. Data was collected on maintenance opioid used prior to starting INF; the character of pain experienced, previous breakthrough analgesia used, method of titration, final maintenance dose of INF; effectiveness and the outcome of the admission. Results were analysed using descriptive statistics.

**Results:** 18 patients had trialled INF between 2012 – 2013 of which 2 patients had INF initiated in clinic and notes were unavailable for 1 patient, excluding them from the study. 12 out of 15 patients (80%) had been on the recommended maintenance opioid analgesia prior to starting INF. INF was started in 13 out of 15 patients (87%) for incident pain. All patients had previously trialled immediate release strong opioids. 6 out of 15 patients (40%) had the INF dose titrated according to the recommended protocol. INF was found to be effective in managing breakthrough pain in 8 out of 15 patients (53%). The mean, final titrated dose was 400 micrograms. No adverse reactions were reported.

**Conclusion:** INF was found to be effective in managing incident pain in more than 50% of the patients in this study. It was found to be effective for use in patients on maintenance opioid therapy where other immediate release opioids had been ineffective. It was also found to be a successful analgesic when utilised in patients outside usual practice.

**Abstract number:** P2-028  
**Abstract type:** Poster

## A Retrospective Study of Use of Methadone for Symptom Control in an Inpatient UK Hospice

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**Background:** Methadone is used in palliative care for neuropathic/complicated pain, neurotoxicity and renal failure.

**Methodology:** A retrospective case note and drug chart review undertaken of 21 patients started on methadone as an hospice inpatient during 2013–2014.

**Results:** 86% of patients had documentation of initiation of methadone by a consultant. 86% of patients were started on methadone for neuropathic/complicated pain. 71% of patients had a record of renal function close to their starting methadone. 76% of patients were already on adjuvant neuropathic medications. Methadone was initiated as a co-opiate in the 47% of patients or as a co-opiate in combination with a loading dose of methadone (28.5%). Most patients did not have their pain assessed with a pain scale tool on initiation and titration. The starting dose of regular methadone ranged from 5–15mg bd. The dose of PRN medication on discharge was lower than on initiation in 33% of patients. In 9.5% of patients it was possible to switch from injection to oral PRN medication. In 33% of patients there was no change in strength of PRN medication used. All patients were on a strong opiate on initiation with Oxycodone and Fentanyl preparations the most frequent. 24% of patients had documented over-sedation leading to dose reduction of methadone. One possible incidence of drug induced psychosis was reported. No sudden deaths were identified. There was variability in the day of titration. First titration after initiation ranged from Day3 to Day8 (mean 4.6) Second titration ranged from day 5 to day 10+ (mode Day7 and Day9).

**Conclusion:** Good practice was identified in documenting initiation of methadone in the majority of cases. The method of initiation and titration was varied, and there was a lack of documentation of pain assessment on initiation and titration. Methadone appears to be a useful medication for pain with very few side effects. Further review of guidelines and review of practice is recommended.

**Abstract number:** P2-029

**Abstract type:** Poster

## Predictors for the Efficacy of Lidocaine in Advanced Cancer Patients with Refractory Abdominal Pain

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**Background:** Abdominal pain including peritoneal carcinomatosis is refractory to opioids and worsens quality of life in patients with advanced cancer. In Japan, lidocaine is used for such refractory abdominal pain, but predictors for the efficacy of lidocaine administration have not been established.

**Aims:** This study aimed to identify predictors for the efficacy of lidocaine in patients with opioid-resistant abdominal pain, including from peritoneal carcinomatosis.

**Methods:** Advanced cancer patients who were systemically administered lidocaine for opioid-resistant abdominal pain between August 2007 and March 2014 were eligible for this study. Patient characteristics and laboratory data were obtained retrospectively from medical record. Analyses were performed to identify predictors for the efficacy of lidocaine administration.

**Results:** Overall, 56 patients were analysed (female, 51.8%; median age, 55.3 years). All patients had taken opioids (median, 263 mg/day; interquartile range, 72–270 mg/day in oral morphine equivalents) before the start of lidocaine use. Lidocaine was effective in 35 of the 56 patients (62.5%). Although 1 case showed mild systemic toxicity from local anesthetic, no serious side effects of systemic administration of lidocaine. Logistic regression analysis revealed female sex (odds ratio (OR), 7.4; 95% confidence interval (CI), 1.9–28.6;  $P=0.004$ ), presence of rebound tenderness (OR, 14.7; 95%CI, 1.6–135.9;  $P=0.018$ ); and hardness of the abdominal wall (OR, 3.8; 95%CI, 1.1–27.8;  $P=0.050$ ) as predictors of lidocaine efficacy.

**Conclusion:** This is the first study to elucidate the efficacy of lidocaine for opioid-resistant abdominal pain in patients with advanced cancer. Predictors for the efficacy of lidocaine were female sex, presence of rebound tenderness, and hardness of the abdominal wall.

**Abstract number:** P2-030

**Abstract type:** Poster

## Multidisciplinary Approach in Attending to Patients under Palliative Care – A Case report

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E. F. patient, hospital record 1101993, male, white, married, 50 years and eight months, coming from Santarém, State of Pará, Brazil, bearer of prostate adenocarcinoma, metastatic to bone, nodal, liver, lung and central nervous system, presenting visual blurring and poorly controlled pain. The patient had an intense neck pain and was using morphine. He was referred to the palliative care service on June 23, 2014 and underwent radiotherapy in the head and neck. The patient had oral and esophageal candidiasis, xerostomia, and pain in the oral region and swallowing. The Department of Dentistry held oral hygiene instruction to decrease tongue coating and combat oral and esophageal candidiasis also using nystatin oral, use of artificial saliva to combat xerostomia, and essential fatty acid for daily moisturising of the lips. It was performed daily intraoral application of lasertherapy to stimulate the production of saliva, decreased xerostomia and pain control. The speech therapy included the evaluation, rehabilitation and guidance aspects of swallowing. The speech evaluation at bedside was with the aid of FOIS scale (Functional Oral Intake Scale), where the patient had grade 3 scale, a total oral intake of a single consistency FOIS was indicated, in this case an exclusive soft diet. The nutrition had the main goal to assist and avoid vomiting, help him to lose the fear of eating choosing food of easy swallowing and digestion, increase calorie intake with less volume as supplements, fractionate the diet for greater acceptance, maintain weight and hydration. After multidisciplinary care the patient developed a decrease and stops vomiting, increased appetite, lost the fear of eating and control of oral pain and swallowing.

**Abstract number:** P2-031

**Abstract type:** Poster

## Pharmacotherapy of Pain among Palliative Elderly Persons in Poland

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**Background:** Pain is one of the most common symptom among elderly subjects, although these are data showing that together with the advanced age both reporting the pain and consuming painkillers is decreasing.

**Aim:** Analysis of pharmacological treatment of pain among elderly nursing home (NH) inhabitants in Poland, in the context of their clinical diagnoses with special attention to patients with dementia.

**Methods:** Analysing data of group of 400 NH inhabitants (313 women and 87 men) at age of 75 or more (average age of  $83.6 \pm 5.9$ ) acquired of CANE program. Among analysed subjects the characteristic of diagnoses and pharmacotherapy, length of stay in NH, Barthel and MMSE scales were done. Analysed group was divided into 2 subgroups depending on MMSE results:

1. MMSE 0–9 points – 107 persons
2. MMSE 10–19 points – 144 persons

**Results:** In the analysed group:

- Average number of diagnosis:  $2.5 \pm 1.2$
- Average number of medication taken:  $5.5 \pm 2.9$
- Average number of prescription drugs:  $4.8 \pm 2.7$
- Average number of OCT drugs:  $0.7 \pm 0.8$

Within the 1 subgroup 18,7% of persons was diagnosed with pain causing diseases. Among

those only 10,3% was treated with analgesics. 29,0 % of the 1 subgroup was treated with neuroleptic drugs (risperidon, promazin, perazin, haloperidol, sulpirid, chlorprotixen, quetiapine).

Within the 2 subgroup 25% of persons experienced pain causing disease. Among those only 15,3% took analgesics. 20,0 % of the 2 subgroup took neuroleptic drugs.

**Conclusion:** Despite the fact that pain causing diseases were diagnosed, only small part of persons with dementia were treated with analgesics. Concomitantly they consumed neuroleptic drugs. It may suggests that anxiety can possibly come from the underdiagnosed and undertreated pain instead of the worsening of the cognitive state. Treatment involving neuroleptics when pain is involved, impairs cognitive functions and can cause vicious circle effect.

## Breathlessness

**Abstract number:** P2-032

**Abstract type:** Poster

## Successful Nursing Support for a Patient with Primary Macroglobulinemia under a Long-term Artificial Respiratory Support

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**Background:** Primary macroglobulinemia is one of blood cancers and its prognosis is poor.

The indication of an artificial respiratory support is controversial, when a patient with this condition shows breathing difficulty. We herein report our support to a patient with primary macroglobulinemia having received a long-term artificial respiratory support.

**Case:** A 50-year female with primary macroglobulinemia was introduced into the palliative care team requiring psychological support nine days after hospitalisation. She showed advanced muscle weakness and neuropathy, which did not improve after four-time plasmapheresis. Her breathing deteriorated progressively, although it was rare complication of primary macroglobulinemia. It was discussed among the palliative care team members whether the introduction of an artificial respiratory support is appropriate in this patient with a malignant disease. Although it was uncertain that she could recover from respiratory illness, an artificial respiratory support was introduced for chemotherapy. The nursing care policy was set to reduce her discomfort as much as possible. She suffered from insomnia and her quadriplegia did not improve during the first two months. In order to encourage her and share the information of her daily changes among the medical staff members and her, a handmade calendar was put in her ward room by the nurses. The continuous effort of reduction of her anxiety and confusion was made during the period of 160-day artificial ventilation. She became free from artificial respiratory support by successful chemotherapy. She discharged from our hospital by walking with a stick 277 days after hospitalisation.

**Conclusion:** The continuous patient encouragement and the share of information among medical staff members and the patient were considered to be effective to rescue the patient from advanced neuropathy related with primary macroglobulinemia.

**Abstract number:** P2-033

**Abstract type:** Poster

## Emergency Department Presentations by People with Chronic Breathlessness

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**Background:** Targeted crisis plans may prevent avoidable hospital attendance/admission for people with acute-on-chronic dyspnoea.

**Aims:** To measure the prevalence of Emergency Department (ED) presentations due to acute-on-chronic dyspnoea and describe care in the ED.

**Methods:** A patient survey and case note review of consecutive attendees arriving by ambulance to the trolley area of a UK ED (sample 1,191; +/-1% error) to find prevalence of presentations: i) by attendees with chronic dyspnoea ii) due to dyspnoea. Measures included: diagnosis, destination post ED, days admitted, previous presentations, duration of chronic dyspnoea, mMRC, clinical record of dyspnoea. Descriptive statistics are used.

**Results:** 1345/2041 (66%) attendees had capacity and 1212 completed surveys (90% response). The prevalence of presentations

i) by attendees with chronic dyspnoea was 35% (424/1212, 95% CI; 32–38%)

ii) due to dyspnoea was 20% (245/1212, 95% CI; 18–22%). 112/237 (47%) had chronic dyspnoea for over 2 years. 159/236 (67%) had mMRC dyspnoea 3 or 4.

There were 4,692 presentations to all ED areas, so dyspnoea bad enough for the trolley area was at least 5% (245/4,692, 95% CI; 4–6%) of all ED presentations.

Case note review of those presenting due to dyspnoea (n=187/245) showed recorded dyspnoea in 113/187 (60%), 59 (32%) were discharged and 128 (68%) were admitted. Median length of stay was 3 days (range=1–44; IQR=1–7); 40/128 (31%) were admitted for 1 day. 88/187 (47%) were first presentations over the last year (median No. presentations/last year =1; range 0–30; IQR 0–2).

**Discussion:** The ED may be a stressful experience and may not be the best place for many with chronic dyspnoea. This high prevalence of acute-on-chronic dyspnoea represents a large burden for EDs and ambulance services. About half (99/187;53%) were either not admitted or only admitted for 1 day and may be those for whom improved dyspnoea care planning between primary and secondary care might reduce avoidable attendances.



Abstract number: P2-034  
Abstract type: Poster

### A Breath of Fresh Air?: Analysis of Short Specialist Palliative Intervention in Non-malignant Breathless Patients

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**Background:** Breathlessness is common in advanced disease. Those with cancer often have good support, compared with end stage non-malignant disease. A multiprofessional short specialist palliative intervention (SSPI) includes symptom management, coping & advance care planning. A visual analogue scale (VAS) pre & post intervention addresses four specific areas: breathlessness, anxiety, sleep quality & energy levels. Opioids for breathlessness now given as slow release morphine (max 30mg/24hrs) rather than immediate release.

**Aims:** To assess appropriateness of referrals, subjective symptom improvement & advance care planning conversations offered.

**Methodology:** Retrospective audit 18 months referrals, for VAS score pairs, subjective assessment of symptoms, GSF registration, ACP discussions, PPC recording & achievement (if died).

**Results:** 52 patients identified – 16 excluded, 14 cancer, 1 DNA, 1 moved away. 36 records reviewed. 90% pulmonary disease, 5% cardiac, 5% MND. VAS score pair recorded 65% – breathlessness reduced 57%, worsened 17%; anxiety reduced 70%, worsened 8%; sleep quality improved 35%, unchanged 65%; energy levels improved 40%, worsened 8%. PPC recorded 94% – home 72%, not home 28%. 44% clinic attenders died, 81% achieved PPC & 62% supported by individualised plan for care. 100% discussed wishes & preferences, ACP discussed 72%, formal ACP by a few, ADRT 8%. DNACPR in place for 15%.

**Conclusions:** Initial poor VAS completion addressed by one doctor being responsible for SSPI. Referral rates increased & inappropriate referrals declined. Multiprofessional approach appears to help patients & carers manage/cope better with daily symptoms. Two patients showed dramatic improvement in breathlessness, anxiety & energy on a second intervention attendance. VAS scale improvements appear more marked with modified release morphine compared to immediate release (audit ongoing). Clinic appears to be encouraging patients to engage in process of advance care planning.

Abstract number: P2-035  
Abstract type: Poster

### The Use of Bedside Sonography in a Mobile Palliative Care Team

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**Background:** Optimal symptom control is essential in palliative care patients, but unnecessary diagnostic procedures should be avoided. There are only few reports in literature about the role of mobile ultrasound machines in this setting.

**Aim:** We investigate the use of bedside sonography (with a V-Scan and a SonoSite 180) in a mobile palliative care team (MPT). What are useful indications? Are the findings of clinical relevance and what are therapeutic implications?

**Methods:** From November 2013 till October 2014 95 US examinations were performed in 60 different patients by doctors of the MPT and prospectively evaluated in regard to indications, results and therapeutic consequences. The majority of patients (86%) were suffering from cancer.

**Results:** The main indication for bedside sonography was dyspnoea (n= 56, 59%), followed by pain (n=27, 30%). The main clinical question was, whether there is fluid in the pleural space or ascites in the abdomen.

As a result of the US examination 29 drainages of ascites and 30 pleural punctures were performed. Other therapeutical consequences were change of medication (e.g. prescription of antibiotics or diuretics after diagnosing pneumonia or pleural effusions) or placing a urinary catheter in a case of urinary retention.

US guided therapeutical interventions can be performed at home with a low risk of complications. Only 2 from 59 patients showed minor complications: One pleural puncture had to be repeated due to a blocked needle, one patient showed a leakage over several days after drainage of ascites.

**Conclusion:** Mobile ultrasound is a well tolerated diagnostic tool. The results of bedside sonography influence our therapeutic procedures. Therapeutic interventions at home can avoid unnecessary hospital admissions, they are safe and result in an immediate symptom relief.

## Fatigue/weakness/cachexia

Abstract number: P2-036  
Abstract type: Poster

### Tampa Scale for Kinesiophobia-fatigue (TSK-F): Translation, Reliability and Validity

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**Objective:** To date, there is no Swedish instrument that measures fear of movement for cancer-related fatigue. This study aimed to translate, test reliability and validity of the Tampa Scale of Kinesiophobia-Fatigue (TSK-F).

**Method:** TSK-F was translated into Swedish and designed to enable the evaluation of test – retest reliability as well as construct-, criterion- and face validity. Twentyfour cancer survivors participating test TSK-F SV.

**Results:** Test-retest (n = 13) showed that the total score of the TSK-F SV is reliable. Kappa analysis indicated a moderate line in 5 out of 17 questions (K = .448 to .527), where the others had no issues or very faint line (K = 0 to 0.389). The description of construct validity with Question and Answer Model (QAM) demonstrates that participants were fairly confident in their responses to the TSK-F EN (median 8.32 out of 10). Criterion validity with FACIT-F was good (r = 0.60, p = 0.028), but there was no statistically significant correlation between the TSK-F SV and “Perceived barriers to exercise,” part of the question “(tiredness or lack of energy) (r = 0.35, p = 0.16).

**Conclusion:** The study results show that the total score on the Swedish version of the TSK-F has good test-retest reliability and concurrent criterion validity against the FACIT-F. Of the 17 questions in the TSK-F only five had a moderate correspondence by kappa analysis. The other questions showed no or very weak consistency. As the study was carried out with few participants, however, the results interpreted with caution.

Abstract number: P2-037  
Abstract type: Poster

### The Effectiveness of Herbal Medicine for the Management of Anorexia in Advanced Cancer Patients – a Systematic Literature Review

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**Background:** Treatment options for anorexia, a common symptom in advanced cancer patients (pts), are limited. Since many cancer patients use herbal medicine (hm, the medical use of whole plant extracts) and hm for the treatment of anorexia has a long tradition in many cultures, there is a need to explore the potential of hm in the management of anorexia in advanced cancer pts.

**Aim:** To identify and appraise the literature on the effectiveness and safety of hm for anorexia in advanced cancer pts.

**Methods:** A systematic search (search terms for advanced cancer, hm and anorexia) in 4 databases and hand search was performed. Controlled/uncontrolled studies in adult advanced cancer pts investigating hm for anorexia (primary or secondary outcome) were included. Quality of the extracted data was assessed using the Cochrane Risk of Bias Assessment tool.

A search in AMED and independent data extraction by a second reviewer is planned.

**Preliminary results:** Of 265 hits, 5 studies met the inclusion criteria (11–243 pts, various cancer types, 2 with single herbs from European, 3 with combinations from Asian hm, 3 RCTs, 2 uncontrolled studies, 2 studies with anorexia as primary, 3 as secondary outcome). Both uncontrolled studies reported improvement of anorexia. 2 of the 3 controlled studies showed no difference, one methodologically poor study with a multiherbal preparation showed a statistically significant improvement. In all studies the herbal preparation was safe.

**Discussion:** Due to the paucity and heterogeneity of the identified studies, no conclusion on effectiveness of hm for anorexia can be drawn at present.

To clarify the role of hm in the management of this burdensome symptom, high quality studies in a clearly defined pt population with a defined disease type and -stage, investigating a specific herb or group of herbs that are traditionally used for anorexia, and using outcomes that capture also the individual pts experience, are needed.

**Funding:** Cantonal Hospital St.Gallen



**Abstract number:** P2-038

**Abstract type:** Poster

## Oral Supplements and Nutritional Support

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### Background:

- Cancer malnutrition is frequent and causes poor patient outcomes.
- Individual dietary interventions can improve nutritional intake.
- Oral supplements provide nutritional support when dietary intake is low.
- Success depends on patient acceptability and compliance.
- Four low-volume oral nutritional products were tested for compliance and palatability.

### Aims:

- Record patient compliance with oral nutritional supplements.
- Measure palatability.
- Test patient tolerance.

### Methods:

- **Compliance:** Seven patient groups (n=20 each) in separate clinical locations consumed a nutritional supplement twice daily for 4 weeks and maintained daily compliance diaries.
- **Palatability:** On days 1, 3 and 7, palatability was rated (1–9) for a. smell, b. taste, c. texture, d. aftertaste.
- **Gastric Tolerance Symptoms:** Daily symptom ratings recorded for 7 days.
- Descriptive statistics analysed compliance, palatability and gastric tolerance.

### Results:

- **Compliance:** ≥90% consumed the amount prescribed across all 4 products for each of 30 days. The remaining participants took at least half the prescribed amount.
- **Palatability:** Palatability ratings indicated all four products were palatable. Range 5.7/9 – 6.7/9 for 7 days.
- **Gastric Tolerance Symptoms:** Tolerance was high with only a few mild symptoms in a small number of patients.

### Conclusions:

1. Oral nutritional supplements are an acceptable and patient friendly way to assist nutrition.
2. Low-volume, nutrient-dense supplements may improve both compliance and dietary intake.
3. Tolerance was good and the effect sustained.

\* Supported by Nualtra Ltd.

**Abstract number:** P2-039

**Abstract type:** Poster

## Investigating the Role of Comorbidity in Cancer Cachexia: A Retrospective Cohort Study

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**Background:** Cancer cachexia is a multifactorial syndrome associated with muscle wasting, weakness, fatigue and poor oral intake. It is both debilitating and common, affecting around 60% of patients with lung cancer. New and promising therapies for cachexia are on the horizon, though these have not typically been tested in patients with cancer who are also elderly, have comorbid illnesses such as chronic obstructive pulmonary disease (COPD), or who are frail. Comorbid illnesses and frailty are common in patients with lung and other cancers and along with ageing, are known to cause muscle wasting in their own right. The impact of ageing, comorbidity and frailty on muscle wasting and survival in patients with lung cancer is not known.

**Aim:** To identify key variables in the development of muscle wasting and shortened survival in patients with lung cancer.

**Methods:** A retrospective cohort study is being conducted using a (UK) national lung cancer dataset from 2008–2010. Demographic and clinical characteristics (relating to lung cancer, comorbid illness and frailty) are being collated along with objective assessments of lean body mass from routine CT imaging (using Slice-O-Matic software).

**Analysis:** The population will be detailed using simple descriptive statistics. The relationship between demographic/clinical characteristics and muscle wasting will be explored by multivariate analysis. These same variables will be assessed regarding their ability to predict overall survival, using a proportional hazards model.

**Results:** Data from approximately 300 patients will be presented.

**Impact:** Developing an accurate picture of cachexia in the context of patients' wider health and function is critical if we are to identify the most appropriate patients for active cachexia management. Importantly, this will also involve identifying the most unwell patients for whom cachexia intervention would be futile, and for whom palliative care should be the priority.

**Abstract number:** P2-040

**Abstract type:** Poster

## Cachexia and Inflammatory Markers in Patients with Advanced Pancreatic Cancer

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**Background:** Chronic inflammation is proposed as an underlying biological mechanism for development of cancer cachexia.

**Aim:** The aim of this study was to evaluate the relationship between cachexia classified by the 2011 consensus definition<sup>1</sup> and inflammatory markers.

**Methods:** Patients with newly diagnosed advanced pancreatic cancer were included. Cachexia was diagnosed when one or more of the following three criteria was determined, weight loss >5% past six months, BMI < 20 and weight loss >2%, sarcopenia (mid upper-arm muscle area by anthropometry (female (F) < 18 cm<sup>2</sup>, men (M) < 32 cm<sup>2</sup>)). At inclusion a wide range of acute-phase response proteins, cytokines and hormones were measured by enzyme immunoassays.

**Results:** Twenty patients (F:5, M:15) were recruited. Median (range) age was 67.5 (35–79) years. All patients received chemotherapy. Median survival from diagnosis was 10 (3–25) months. Upon inclusion 11 (55%) patients were classified as cachectic. Acute-phase response proteins, cytokines and hormones among non-cachectic and cachectic patients are shown in the table. All p-values were <0.05.

	No cachexia, n=9 Median (range)	Cachexia, n=11 Median (range)
CRP (mg/ml)	12.1 (1.2–51.9)	2.5 (0–49.6)
IL-6 (pg/ml)	3.9 (0.7–34.6)	2.5 (0.5–19.5)
IL-10 (pg/ml)	0.6 (0.0–3.4)	0.9 (0–7.7)
TNF-α (pg/ml)	6.6 (4.1–22.7)	10.1 (3.3–17.9)
INFγ (pg/ml)	0.1 (0.0–13.6)	0.1 (0–0.8)
Adiponectin (μg/ml)	7.4 (5.9–15.6)	9.5 (3.9–26.0)
Leptin (ng/ml)	1.1 (0.3–23.9)	2.1 (0.3–9.8)
IGF (ng/ml)	70.1 (7.7–128.2)	80.1 (24.6–115.8)

[Levels of inflammatory markers by cachexia]

**Conclusion:** Patients with advanced pancreatic cancer diagnosed with cachexia immediate after cancer diagnosis did not have higher levels of inflammatory markers than non-cachectic patients.

<sup>1</sup>Fearon, K., et al., Definition and classification of cancer cachexia: an international consensus. *The Lancet Oncology*, 2011. 12(5): p. 489–499

## Other symptoms

**Abstract number:** P2-041

**Abstract type:** Poster

## Efficacy of Subcutaneous Ranitidine via Syringe Driver in Patients with Intractable Dyspeptic Pain

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**Background:** Dyspepsia is a common problem and is frequently caused by gastro-oesophageal reflux disease (GORD) or gastritis. However, it is also related to cancer of upper Gastrointestinal tract as well as gastric stasis due to bowel obstruction. In these cases, if the patients were unable to swallow medications or had intractable nausea, they were administered subcutaneous Ranitidine. Ranitidine is a competitive, reversible inhibitor of the action of histamine at the histamine H<sub>2</sub>-receptors found in gastric cells, indicated for use in dyspepsia.

**Aims:** To observe the response of dyspeptic pain in patients with malignant diseases when they are unable to tolerate oral medications.

**Patients and methods:** Prospective study of 22 consecutively admitted patients with Ranitidine syringe driver over one year period.

**Results:** Out of 22, there were 13 males and 9 females with an average age of 68 years (range= 46 to 81). They were diagnosed to have Gastric cancer (10), Oesophageal cancer (6) or Malignant Bowel obstruction (6). Pain was recorded by Numeric Rating Scale (NRS 0–10, with 0 being no pain). 4/22 started Ranitidine subcutaneously 50 mg whereas 18/22 were started on 150 mg. Other medications used in same syringe driver were Metoclopramide, Cyclizine, Haloperidol, Midazolam, Hyoscine Butyl Bromide, Octreotide or Levomepromazine. 10/22 reported improvement in NRS (2 – 8 drop). 4/22 improved on non-verbal assessment as they were too poorly to score. It was not possible to record response in 6/22. 2/22 continued to have same degree of pain. Local skin reactions were noted in 4/22 patients.

**Conclusion:** Patients with dyspeptic pain may respond to Subcutaneous Ranitidine when oral route is not appropriate. Ranitidine can be mixed with most medication in Syringe driver. Local reactions or side-effects were not clinically significant.

**Abstract number:** P2-042  
**Abstract type:** Poster

## Interventions for Respiratory Hypersecretion in Palliative Care Patients – A Systematic Review

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**Background:** Chronic respiratory hypersecretion is a common and distressing symptom for palliative care patients. Yet most research on hypersecretion at the end of life focus mainly on death rattle.

**Aim:** To synthesise the existing evidence evaluating interventions for respiratory hypersecretion in patients in the last year of life (excluding death rattle).  
**Study design:** A systematic review was conducted using Medline, Web of Science, CINAHL and 5 other databases to identify randomised controlled trials (RCT) and observational studies (OS), published prior to August 2013. Titles and data extraction were completed independently by two reviewers.

**Results:** 842 papers were identified, of which 18 met the inclusion criteria. Citation tracking and reference searches resulted in an additional 5 papers. Interventions included mechanical insufflation-exsufflation -MIE (16) and expiratory muscle training (2). Studies with MIE mainly assessed patients with neuromuscular diseases. One RCT with a small sample found that MIE increased lung vital capacity. OSs encompassing MIE showed an increase in peak cough flow, which may explain improved oxygenation, higher survival rates, less complications and need for tracheostomy. Two RCTs assessed the expiratory muscle training in patients with multiple sclerosis, and found higher maximum expiratory pressures and an improved cough efficacy, subjectively assessed by the Pulmonary Index. Other interventions were manually assisted cough (7), tracheotomy (4), chest physiotherapy (3), suctioning (4), air stacking (5), electrical stimulation of abdominal muscles (1), nebulised saline (2), positive expiratory pressure masks (3), percussive ventilation (2), high frequency chest wall oscillations (1).

**Conclusion:** The evidence gathered was largely in support of MIE, but there was insufficient high-level evidence to make strong recommendations.

**Financial support:** CAPES – Brazil.

**Abstract number:** P2-043  
**Abstract type:** Poster

## The Management of Paraneoplastic Sweating in a Palliative Care Setting

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**Background:** Excessive sweating is an unpleasant symptom experienced by patients with advanced malignancy. While the causes of sweating in this population are multifactorial, management of paraneoplastic sweating has proved challenging. Existing evidence for treatment of paraneoplastic sweating in palliative populations is poor.

**Aims:** To review and summarise the evidence for treatment options in the management of paraneoplastic sweating. To develop a clinical practice guideline for paraneoplastic sweating.

**Methods:** A targeted literature search was completed. Search terms were 'sweating in palliative care', 'hyperhidrosis in palliative care', 'paraneoplastic sweating'. Drugs used to treat this phenomenon were also entered in conjunction with 'hyperhidrosis' or 'paraneoplastic sweating'. Seven relevant articles were identified, dating from 2000 to 2013. Local guidance documents were obtained from St Elizabeth's Hospice and St Christopher's Hospice and the Palliative Medicines Information Service of Our Lady's Hospice in Harold's Cross for review.

**Results:** Existing evidence for the treatment of paraneoplastic sweating in palliative populations is poor. There have been minimal publications and existing evidence is largely anecdotal. Many of the clinical trials were methodologically flawed; underpowered, uncontrolled and unblinded. Outcome measures were often non specific or unvalidated and little accountability demonstrated in regard to recruitment bias or drop outs. However, promising results from some case studies could provide hypotheses for future research.

Existing publications and guidance documents were reviewed and utilised in the development of a local practice guideline for the management of paraneoplastic sweating.

**Conclusions:** Paraneoplastic sweating remains a distressing symptom for patients and families. It is a phenomenon that remains under represented in the medical literature. Further studies are urgently required to support pharmacological management strategies.

**Abstract number:** P2-044  
**Abstract type:** Poster

## The Use of Subcutaneous Levetiracetam for the Control of Seizures in Adults at the End of Life

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**Aim:** Management of seizures in the dying patient is challenging. Seizures have been reported in 35 to 50 percent of brain tumor patients in the last month of life and cause distress to patients and families. As patients approach end of life, increasing dysphagia may warrant adjustments of oral therapy. Subcutaneous Levetiracetam is a suitable first line anti epileptic drug (AED) in patients who are unable to take oral AEDs and require seizure control without sedation.

**Study population:** Patients presenting with new or recurrent seizure who are unable to take anticonvulsants by the oral route and, in whom high dose midazolam is deemed inappropriate by the medical team.

**Methods:** A prospective case series of patients on SC Levetiracetam in the palliative care inpatient unit and community palliative care teams. Patients selected by their medical consultant as being suitable for inclusion. A survey of routinely collected data and documentation of patient response to Levetiracetam therapy. Secure data management employed.

**Results:** 10 patients accrued. Average age 66years. Three patients had 1\* CNS malignancy,

one COPD and epilepsy, six malignancy with cerebral metastasis. Two patients had first seizures, eight had recurrent seizures. Nine patients were on baseline AED (Kepra in 8/10 patients). A 1:1 PO: SC conversion ratio was employed. SC Levetiracetam was commenced for patients who were NPO and deteriorating but aware. Median starting dose 1100mg/24hr, range 500–2000mg/24hr. All patients had seizure control at 24hr. One patient required titration on day three. Average duration of therapy 3.6 days, range 1–7 days. No site reactions or adverse reactions noted.

**Conclusions:** Levetiracetam is a suitable first line anti epileptic in patients who require seizure control without sedation but are no longer able to take oral anti epileptic medications.

**Abstract number:** P2-045  
**Abstract type:** Poster

## Study the Use of Continuous Ondansetron Infusion to Control Nausea in Patients with Hematologic Malignancies

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**Background:** Persistent nausea is a common side effect in patients receiving chemotherapy for hematological malignancies.

**Aims:** Evaluate the efficacy of continuous infusion of ondansetron in managing uncontrolled nausea in patients with hematological malignancies undergoing chemotherapy.

**Methods (design, data collection, analysis):** A retrospective chart review is being conducted to study the effectiveness of continuous infusion of ondansetron. This intervention was used in patients who had unsustained response to 4mg of intravenous ondansetron given intermittently (typically every 4 hours). They were then placed on an intravenous infusion of ondansetron at 1mg/hr. The data points being collected are: patient's demographics (including age, sex, and ethnicity), diagnosis, chemotherapy start and stop date, date of transplant (if transplanted), start and stop date of ondansetron infusion, use of as needed antiemetic 72 hours prior to start of ondansetron drip, use of as needed antiemetic 72 hours after the start of ondansetron drip, use of additional antiemetics, efficacy as documented in patient chart, EKG (if collected after the start of the ondansetron drip), headache as documented in patient chart, list of concomitant medications that can prolong QTc interval (including fluoroquinolones, macrolides, azoles and amiodarone).

**Results:** Our clinical experience suggests that continuous infusion of ondansetron is clinically effective in treating persistent nausea responsive to intermittent doses of the medication. Results will be presented at the EAPC conference.

**Conclusion / Discussion:** We anticipate our study to confirm our clinical observation that intravenous ondansetron infusion is a potentially safe and effective intervention in controlling persistent nausea in those patients that respond to its intermittent use with unsustained effects. Prospective studies will be needed to further validate our findings.

**Abstract number:** P2-046  
**Abstract type:** Poster

## Subcutaneous Use of Levetiracetam in Palliative Care – A Case Report and Review of the Literature

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**Introduction:** Within Palliative Care there are patients with a known past medical history of epilepsy and the need for anticonvulsive treatment. Sometimes it can be difficult to administer drugs to prevent or treat epileptic seizures without an intravenous access or an existing percutaneous endoscopic gastrostomy tube (PEG).

**Aim:** To present a patient case with subcutaneous administration of Levetiracetam to prevent and relieve suffering from status epilepticus and to provide an overview of the scientific literature on the topic.

**Method:** A case report with the use of subcutaneous Levetiracetam is presented. In addition a literature search was performed and an overview of the current literature on the topic will be given.

**Results:** A case of a patient with advanced Friedreich's ataxia who previously had refused life-prolonging treatment using advanced care planning is presented. Before admission to hospital due to epileptic seizures the patient lived in a nursing home because of the need for nursing care around the clock. The main problem was the application of anticonvulsive medication to prevent suffering from epileptic seizures and status epilepticus with intravenous access or PEG. After an ethics consultation with participation of representatives from the hospitals ethics committee, the neurology department, the Palliative Care Team and the patients mother it was concluded to respect the patients wishes. In order to prevent seizures the subcutaneous application of Levetiracetam 2g daily was established with good effect.

**Conclusion:** The subcutaneous use of Levetiracetam seems to be a valuable treatment option in Palliative Care when no other application form is feasible. Although there are no clinical studies our case report supports other published case reports that subcutaneous Levetiracetam is a treatment option in Palliative Care patients with the need for anticonvulsive treatment.

**Abstract number:** P2-047  
**Abstract type:** Poster

## Clinical Usefulness of the BCM (Body Composition Monitor) Method in Advanced Cancer Patients under Hospice Care

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**Background:** BCM is fast, painless device that determines individual fluid status and body composition (lean and adipose tissue mass) employing the bioimpedance spectroscopy techniques. Some authors suggest that the accumulation of body fluids detected in BCM method is a factor of shorter expected survival time. Therefore, BCM method seems to be useful tool especially in the group of advanced cancer patients and may have an impact on both therapeutic decisions and effective communication with the patient and his family. It has not been tested in terminal stage cancer patients so far.

### Aims:

1. evaluation of the technical possibilities of implementation of BCM in advanced cancer patients
2. comparison of the BCM hydration and nutrition status measurements with physical examination and laboratory tests
3. to find whether BCM method measurements correlate with the survival time.

**Methods:** The survey is conducted among adult cancer patients in terminal stage consecutively admitted to stationary Hospice in Sopot. After informed consent patient's hydration and nutritional status is assessed with: clinical scale of hydration based on physical examination, Subjective Global Assessment scale, hand grip and arm circumference measurements, BCM device. Blood samples are collected for laboratory indicators of nutrition.

**Results:** We assessed 68 subjects. Due to both technical and clinical reasons [peripheral oedema, ascites, lower limb amputation, severe shortness of breath, inability to lie down on his back, agitation and agonal status] 23 patients were not tested. In 12 patients we observed poor measurement quality.

**Conclusions:** It is difficult to obtain good quality measurements with BCM. Preliminary observations show that more than half of the patients could not be evaluated properly. Statistical analysis will be carried out after examining approximately 50 subjects. The predicted survival time on the basis of BCM measurements from natural causes can be determined at a later date.

**Abstract number:** P2-048  
**Abstract type:** Poster

## The Effect of "Therapeutic Tactile Touch" Practices Done for the Patients in the Intensive Care Units upon their Fears, Anxieties and Pain Levels

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**Background and objectives:** Being at intensive care unit is a rather traumatic and fearful experience for the patients. In intensive care units; on the one hand, condition of the patients may quickly change, there may be ambiguities and death threat; on the other hand, sounds of monitoring systems, ventilators, liquid and/or medicine infusion pumps lead to anxiety and fear among the patients. These feelings experienced by the patients may negatively affect not only many parameters but also patient's pain perception. The study was planned to determine the effect of "therapeutic tactile touch" practices done for patients' upon their fear, anxiety and pain levels.

**Methods:** The study was conducted at adult general intensive care unit of Istanbul Medipol Mega University Hospital. 11 patients who were treated at the general intensive care unit for at least 24 hours, were eligible for the study criteria and accepted to participate, were conscious (intubated or extubated) were included in the study. They were daily given a 30-minute "therapeutic tactile touch protocol" for four days. Visual materials which were designed in line with the literature and through which patients could manually point the emotion experienced were used before and after the protocol in order to assess the anxiety and fear experienced by the patients. Meanwhile visual analogue scale for pain was used to assess the pain perception of the patients.

**Results:** It was found out that before and after the protocol, there were statistically significant differences between patients' mean scores obtained from visual analogue scale for pain and facial expression pain scale and their mean anxiety and fear scores and that patients' pain, fear and anxiety levels reduced ( $p < 0.05$ ).

**Conclusions:** We believe that using therapeutic tactile touch practices should be used by health care personnel – particularly by nurses – in order to eliminate intensive care patients' pain, fear and anxiety as a complementary therapy.

**Abstract number:** P2-049  
**Abstract type:** Poster

## Palliative Care Inpatient Oncology

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**Introduction:** The current model of Palliative Care in oncology (PC) needs a dynamic and rapid response to cases requiring hospital-based support teams. In our hospital the Palliative Rapid Response Team (PRRT) was formed for the growing number of cases complex biopsychosocial and spiritual, with the mission of supporting the medical team in the care of the patient and his family for taking making at the end of life.

**Methods:** Were included all patients treated in the ward of the palliative care unit from January to June 2014.

**Results:** Were evaluated 120 patients, 50% were women, mean age 53.2 (SD16.47) years. The most frequent symptoms were pain (24.3%), dyspnea (16.2%) and delirium (13.5%). The time of hospital admission to the request for consultation service had an average of 11.6 (SD 21.74) days and the hospital stay was 15.8 (SD 29.29) days. The mean of Karnofsky was 40%. Morphine was the most indicated analgesic (40%). 40% died in hospital and extra-hospital survival was 5.5 (SD 6.3) days on average.

**Conclusions:** Patients are referred to CP after 12 days of hospitalisation, the SPRS has on average 5.5 days to execute the strategic treatment plans for stabilisation and hospital discharge. Collaborative work with Oncology optimises advanced cases and promotes timely referral, impacting favorably quality of life and quality of death.

**Abstract number:** P2-050  
**Abstract type:** Poster

## Gender, Social or Psychology Related Risk Factors for Developing Delirium at the End-of-Life: A Literature Study and Case Report

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**Background:** Delirium is cause of much suffering. If professionals were able to predict risk factors for developing delirium it may be possible to prevent some of the cases. In the daily clinic we found that more men, more patients with complicated social situations and premorbid personality develop delirium.

### Aim:

- 1) To explore gender, social and psychological risk factors for developing delirium as described in the literature
- 2) To study whether gender, personality traits and social problems are risk factors.

**Methods:** Pub Med was searched from 1990 to 2013. Inclusion criteria: Original data on adult patients, diagnosed delirium.

**Case-review** on 50 consecutive patients referred to the specialised palliative care team in Herning, Denmark. The patients were grouped into two groups: One with delirium (D+) and one without (D-) Two-sided Fisher's exact test was used looking at age, gender earlier psychiatric problems and social problems. P-values  $< 0.05$  were considered significant.

### Results:

**Literature search:** One study found male gender as a risk factor. No evidence for social or psychology related risk factors was found.

**Case-review:** Information on delirium was lacking in 20 cases. Of the remaining 30 cases 18 patients developed delirium (D+) and 12 did not(D-).The proportion of males in D+ were 61 % and in D- 33%  $p=0.26$ . Of the 18 delirious patients one had earlier psychiatric problems (6%) and in D- none had earlier psychiatric problems. Three patients in D+ had social problems (17%) versus three in D- (25%)  $p=0.66$ . It was not possible to examine patient's personality trait retrospectively.

**Conclusion:** The literature study did not identify significant social or psychological risk factors, but male gender seems to be a potentially factor to consider as the case review also indicate. More knowledge is needed to determine whether social or psychological factors are risk factors for developing delirium.

**Abstract number:** P2-051  
**Abstract type:** Poster

## Variation in the Incidence of Agitated Delirium during the Day in a Palliative Care Unit

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**Background:** In the literature regarding delirium and agitation in palliative care, there are references to their worsening as the hours of the day flow from afternoon on, with an inversion of the awake-sleep cycle.

**Aim:** To study the incidence of agitation during the day in a palliative care unit.

**Methods:** We studied the frequency of the use of our protocol for the control of agitation during the day from June 18, 2007, to December 31, 2013.

**Results:** During the period in study 1558 were admitted and the protocol was used in 135 (9%). 102 (76%) were males and the mean age was 65.75 years (SD  $\pm$  12.09). The most frequent diagnosis was head and neck cancer, 37 (27%), followed by lung cancer, 27 (20%). The protocol was used correctly 584 times, from 1 to 31 times in each patient, median 3 times. Differences in the incidence of agitation during the day were observed. The day was divided in periods of 2 hours with a 48.7 of expected episodes of agitation per period. However, the number of observed episodes was higher than the expected one in some periods: 22:00–23:59, 100; 0:00–1:59, 92; 2:00–3:59, 80; 4:00–5:59, 65. In all other periods the number of episodes was lower than the expected one. The chi-square goodness of fit test proves that the differences are statistically significant ( $p < .001$ ).

**Conclusion:** This study confirms that the episodes of agitation are more frequent at night.



**Abstract number:** P2-052  
**Abstract type:** Poster

## Patients' Experience of Impaired Sleep and Affecting Factors at an Inpatient Specialized Palliative Care Unit

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**Background:** Sleep-wake disturbances and insomnia are often described in patients with advanced disease and in palliative care. Factors such as anxiety, rumination, dreams, and pain are reported to influence the sleep quality. Insomnia and disturbing factors are often assessed by single questions or validated instruments. However, patients' own experiences of factors affecting their sleep and sleep quality are often not described or clinically assessed.

**Aim:** To investigate how patients in inpatient specialised palliative care perceived their sleep, what affected a disturbed sleep, if they had dreams and in what way they experienced them.

**Method:** The study was conducted during five days at two inpatient palliative care wards. Every morning all patients were asked to answer a study specific questionnaire including questions such as: how did you sleep tonight; did you dream anything; if you slept badly, what do you think was the cause, with selected variables; and space for open comments. The wards together had 39 beds with 195 possible patient nights during the study period. Descriptive statistics and a thematic qualitative analysis were used.

**Results:** Preliminary results showed that 160 questionnaires were handed out to 53 eligible pts and 89 questionnaires (56%) were answered. Thirty-four percent of the patients reported sleeping less well or badly. Of these 60% reported difficulties falling asleep; 53% early awakening; 40% pain; 43% ruminations. Ruminations were described as: the situation of being severely ill; the end of life; whom to ask for help. Dreams were described as: dreams in vivid colors; a lot of dreams; about the situation and the family. Anxiety, worries, pharmacological aspects and environmental factors were other affecting factors seen in the comments.

**Conclusion:** Several factors may affect patients' sleep quality and this study highlights the importance of asking patients about their own experiences as well as focus on ruminations and dreams.

**Abstract number:** P2-053  
**Abstract type:** Poster

## Possibility of Use of Bedside Ultrasound Examination in the Patient's Home by Use Focused Assessment Sonography Protocol in Palliative Care

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Bedside ultrasound is valuable, but it is difficult to provide in hospices. We conducted a survey in which employees hospices evaluated the protocol FASP designed for ultrasound examination of palliative patients. The aim of the study was to determine if the use of portable ultrasound at home by a doctor is justified and, if so, what should be assessed by ultrasound at the patient's home.

**Methods:** The study was conducted in a group of 60 employees in palliative care departments, 78% of doctors, 20% nurses. 2% other. Surveys included questions on general and specific; as experience of working in a hospice, education, specialty, appropriateness and need an ultrasound, ultrasound experience, the scope of the study, which organs should be investigated. The responses received were subjected to statistical analysis using ANOVA and Wilcoxon test.

**Results:** Longer length of service in a hospice but the young age of the staff is a greater need for the use of ultrasound  $P < 0.05$ . Even a brief experience with ultrasound in the past, this willingness to use ultrasound in their patients,  $p < 0.001$ . No equipment is a fundamental limitation of the use of ultrasound  $p < 0.001$ . Lack of training is a major constraint for all respondents, but only 75% of them will participate in the training, if they were available.  $P < 0.05$ . The majority of 75% respondents, want to evaluate the fluid in the abdomen, and intestinal motility and condition of the gallbladder,  $p < 0.001$ , minority 25% would like to assess liver and kidney and bladder  $P < 0.05$  15% see the need to use ultrasound in the cannulation of vessels, and nerves blocks. In this group, 90% were anesthesiologists  $P < 0.05$ .

**Conclusions:** Persons under 40 years see the need to study FASP. Only those who had emergency ultrasound courses will explore in the patient home. Primary need is the assessment of fluid in the abdomen and bowel evaluation. Examination of the pleura, the assessment of vessels and nerves is secondary.

**Abstract number:** P2-054  
**Abstract type:** Poster

## Dying Patients Nursing Activities in the Institutional Care in the Czech Republic

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**Background:** In the Czech Republic (CR), up to 80% chronic disease and 64% oncologic patients dying in a hospital or Long-term care facilities (LTCF). Nursing interventions Dying care and Spiritual support allow moderate patient's physical, psychosocial, and spiritual suffering and support family also in the institutions.

**Aims:** The study aims to determine the frequency of nursing activities in dying patients care in different facilities in the CR.

**Methods:** (design, data collection, analysis)

The cross-sectional study with ad hoc questionnaire with Likert's scales and activities of Dying care and Spiritual support interventions was performed. The set composed of 592 nurses (mean age 38.5 years; mean practice 16.0 years; 6 types of facilities – LTCF, hospice, oncology, geriatric, home for elderly, intensive care unit). Kruskal–Wallis and Mann–Whitney tests and Spearman correlation were used for statistics.

**Results:** Treating the patient with dignity had the highest frequency in most facilities (mean value: 1.11–1.30). Follow pain was a priority in hospice and intensive care unit (mean value: 1.11–1.25). To support the family's efforts to remain at the bedside was the second most frequent activity in a hospice (mean value: 1.15) with significantly lower frequency in other facilities. The only but weak correlations were detected between gross somatic dimension score ( $M=7.18$ ,  $SD=5.05$ ) and 1/ nurses age ( $r=-0.110$ ,  $p=0.007$ ), 2/ the length of practice ( $r=-0.087$ ,  $p=0.033$ ). The frequency of activities in psychosocial, spiritual and religious dimensions in hospice significantly differ in comparison with other facilities ( $p < 0.05$ ).

**Conclusion/ discussion:** The psychosocial, spiritual and religious activities in the care of the dying patients are used infrequently except of hospice in the CR. There is a need to focus more research on identifying factors that enable their implementation in all health facilities in the CR.

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**Abstract number:** P2-055  
**Abstract type:** Poster

## Longitudinal Assessment of Cognitive Functioning in Patients with Cancer in Specialized Palliative Care

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**Background:** Prospective studies with objective assessments of cognitive function (CF) in patients with advanced cancer are relatively few. Thus, the scientific evidence regarding status of CF over time is limited.

**Aim:** To assess the CF of patients with advanced cancer over 3 months of palliative treatment.

**Methods:** This prospective longitudinal investigation derives from the European Palliative Care Cancer Symptom study, which was conducted in Europe, Canada, and Australia (2011–2013). Inclusion criteria: patients with advanced cancer, in a palliative care programme, >18 years, able to participate for at least 1 assessment post-inclusion. Assessments occurred at inclusion and every 4 weeks for another 3 months, or until death. CF was assessed with a reduced version of Mini Mental State Examination (MMSE), including items on year, date, backward spelling, and copy a drawing. The total score is 8 and a score  $\leq 4$  indicates cognitive dysfunction. Only patients with MMSE scores on all four assessments were analysed.

**Results:** The total sample was composed by 1739 patients from 12 countries, with 608 having complete MMSE cognitive data on T1–T4 (59% female, mean age=66 years ( $SD=12$ ), 65% living without a partner and 69% with  $\geq 10$  years of schooling). The majority were outpatients (78.5%) and had metastases (83.2%). The most frequent cancer diagnoses were breast (27%), respiratory (21.4%), and GI-cancers (20.7%); 83% had metastases, mean Karnofsky performance status was 72.9% ( $SD=14.5$ ). Total MMSE mean scores varied from 7.1 ( $SD=1.5$ ) to 7.2 ( $SD=1.5$ ) and with about 7–8% constituting the ones with low scores.

**Conclusion:** MMSE mean total score did not worsen over time, and the proportion of patients with poor CF remained similar.

**Abstract number:** P2-056  
**Abstract type:** Poster

## Treatment of Non-convulsive Status Epilepticus as Life Prolonging Therapy in Patients with Primary Brain Tumors – The Opinion of the Patients and Relatives

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**Aims:** Non-convulsive status epilepticus (NCSE) is epileptic activity which lasts for more than 30 minutes. Especially patients with primary brain tumors are at risk to develop NCSE. Treatment of NCSE is effective in about 60 % of patients but is considered a life-prolonging therapy. Therefore we intended to evaluate whether treatment of NCSE is in accordance with advance directives and the wishes of patients and relatives.

**Methods:** We have systematically evaluated patients with primary brain tumors who had at least experienced one prolonged epileptic seizure and who had an advance directive which considered no life-prolonging therapy after loosing consciousness because of tumor progression. After a standardised explanation of NCSE we have explained pharmacological treatment options and escalation of therapy by transferring patients to an Intensive Care Unit (ICU). The patients were asked whether they feel that this situation has been included in their advanced directives and whether they would prefer treatment or non-treatment in this situation. Additionally, the relatives were asked separately the same questions regarding the treatment for the patient.

**Results:** We have identified 15 patients with glioblastoma and 2 with astrocytoma who had at least experienced one prolonged epileptic seizure. Age has been between 41 and 72 years, M:W = 11:6. All patients had relatives who were willing to participate. All patients and relatives wanted to have life-prolonging therapy in case of NCSE, even if consciousness could be gained only for a few days. However, further escalation of therapy with transfer to an intensive care unit (ICU) has been denied by all patients and relatives.

**Conclusions:** Patients and relatives want to have an initial treatment of NCSE to give the life more days. Further escalation of therapy and transfer to an ICU has been refused.



**Abstract number:** P2-057

**Abstract type:** Poster

## Does a Pacemaker Lengthen the Dying Process in Palliative Care Patients?

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**Background:** Many palliative care patients and their proxies, but also health care providers frequently wonder if the presence of a pacemaker (PM) will lengthen the dying process of the patients. The American Heart Rhythm Society panel addressed the problem by clarifying the legal and ethical status of deactivating cardiac devices. The consensus statement also advises physicians on how to communicate with patients and families about whether to turn off a cardiac implanted device and they do not make a difference between a defibrillator and a PM.

**Aim:** The objective of this study is to explore if there what is any objective clinical evidence that a PM will lengthen the dying process in palliative care patients.

**Data collection:** The duration of stay in the palliative care unit (PCU) until death 1600 patients is calculated and patients with (n = 33) and without (n = 1567) an implanted pacemaker are analysed.

The results are: with PM / without PM:

-Median number of days in PCU: 6.5/10d.

-Mean number of days in PCU: 14.1/25d.

-Mean age: 81.1/71.5y. with a Man/women ratio: 1.56/1.18

-Mean number of days in PCU - non-oncology: 4.5/47.1d.

-Mean number of days in PCU-oncology patients: 17.1/23.1d.

-Mean number of days in PCU for 70–79y. old pts – non-oncology: 4.5/8.5d.

-Mean number of days in PCU for 70–79y. old pts – oncology patients: 9.4/24.8d.

-Mean number of days in PCU for >80y. old pts – non-oncology: 4.5/70.2d

-Mean number of days in PCU for >80y. old pts – oncology patients: 21.9/20.5d.

**Conclusion:** There is not any clinical evidence in this analysis that an implanted PM lengthen the dying process in palliative care patients. Only for cancer patients >80years there is not any difference in duration of stay in the PCU, but for all other categories life patients with an implanted PM much shorter than patients without a PM.

**Abstract number:** P2-058

**Abstract type:** Poster

## Analyses of Opioid-induced Adverse Effects Based on PMDA Japanese Adverse Drug Event Report Database (JADER) in Japanese Patients Receiving Palliative Care

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**Introduction:** The Japanese Adverse Drug Event Report database (JADER) is a computerised information database designed to support the Pharmaceuticals and Medical Devices Agency's (PMDA) post-marketing safety surveillance program for all approved drug and therapeutic biologic products in Japan. Potent opioid analgesics are applicable for the treatment of severe pain, especially in cancer patients. Management of opioid-induced adverse effects is important to continue treatment with opioids because these drugs are associated with a variety of adverse effects, such as delirium and respiratory depression. However, information regarding these adverse effects in Japanese patients is limited. Therefore, we searched and analysed JADER (292,720 reviews; period of 2004–2013) to acquire information related to the adverse effects induced by potent opioids such as morphine, fentanyl, and oxycodone.

**Methods:** Cases with adverse effects associated with morphine, oxycodone, and fentanyl for palliative care were extracted from JADER, and the types and frequencies of the events for each analgesic were analysed.

**Results and discussion:** Results showed that a lot of common adverse effects were found among the three opioids. However, the order of their frequency differed among the analgesics. In the principal component analysis, the property of morphine was intermediate of fentanyl and oxycodone. These findings may contribute to the safe and effective pain control for patients receiving medical treatment with potent opioid analgesics.

**Abstract number:** P2-059

**Abstract type:** Poster

## Ultrasound-guided Rectus Sheath Block for Improvement of the Abdominal Distension Feeling

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We report a case in which abdomen distension feeling and discomfort of the abdominal wall caused by malignant ascites were relieved by ultrasound-guided rectus sheath block.

**Case report:** A male patient in his 50s developed gastric cancer with malignant ascites experienced abdominal distension feeling, but didn't have nausea, dyspnea, poor mobility, and limb edema. He had inadequate symptom control with diuretic therapy and abdominal paracentesis. His distension feeling was improved temporarily by ultrasound-guided rectus sheath block. Then a percutaneous catheter used to administer an infusion of 0.25% ropivacaine triweekly until his death 20 days later.

**Conclusion:** Abdominal distension feeling is one of varied symptoms of severe ascites and it is difficult to management. The ultrasound-guided rectus sheath block could be used to relieve it on a case-by-case basis.

**Abstract number:** P2-060

**Abstract type:** Poster

## Parenteral Hydration: Review of Prevalence and Rationale in Hospice Inpatients

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**Background:** Decreased oral intake of fluids in the last days to weeks of life is common due to anorexia, nausea, dysphagia and/or delirium. Parenteral hydration (PH) may be administered to reduce the risk of dehydration or to manage symptoms. To date, there are no established standards for hydration at the end of life. Each patient's circumstances must be individually assessed.

**Aims:**

1. Evaluate the prevalence of PH in hospice inpatients
2. Assess documentation of PH rationales and route of administration
3. Determine outcome after 48 hours of fluids

**Methods:** A retrospective chart review of 102 consecutive deaths between January and April 2013 was conducted. A data recording form captured hydration episodes. Descriptive statistics were generated by Microsoft Excel.

**Results:** 31/102(30%) received PH during their admission. In 19/31(61%), PH was administered intravenously. 7/12(58%) on subcutaneous fluids received one litre of fluid over 12 hours; a rate that is higher than recommended by clinical guidelines. 58 hydration episodes were recorded. Of 58 episodes, 51(88%) had a start rationale, 36(62%) had a stop rationale and 41(71%) had an outcome recorded. 24/41(55%) outcomes reported an overall improvement post hydration.

**Discussion:** 30% of hospice patients received PH, which contrasted with the North American literature on the topic. Physician preference for intravenous route was evident despite literature suggestions that subcutaneous is preferable. Physician documentation of start rationales was superior whereas nurses recorded stop rationales and patient outcomes more frequently.

**Conclusions:**

1. Parenteral hydration is frequently prescribed, with the intravenous route most common
2. Over half reported clinical benefit within 48 hours
3. Start rationales were most likely to be recorded
4. Opioid toxicity was the commonest indication
5. Future studies should prospectively evaluate the effect of hydration on symptoms and quality of life

**Abstract number:** P2-061

**Abstract type:** Poster

## Orthostatic Hypotension in the Diagnosis of Autonomic Nervous System Dysfunction in Cancer

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**Background:** Limited studies suggest autonomic nervous system dysfunction (AD) is common in advanced cancer. It predisposes to multiple problems that include blackouts, falls, fatigue & sudden death. Orthostatic hypotension (OH) is a known feature of AD; a fall in blood pressure (BP) of 20 mmHg systolic or 10 mmHg diastolic within 3 minutes of standing. OH that persists beyond 3 minutes suggests severe AD. The prevalence in cancer remains unknown.

**Aims:**

1. Evaluate the prevalence of orthostatic hypotension in hospitalised cancer patients
2. Determine the proportion with persistent orthostatic hypotension
3. Examine the relationship between orthostatic symptoms and hypotension

**Methods:** A prospective observational study was conducted. Consecutive oncology inpatient admissions to a tertiary referral centre were recruited over 4 weeks. Autonomic symptoms were evaluated by questionnaire. OH was assessed by one Active Stand Test. Postural BP and symptoms were recorded. Data was recorded in Microsoft Excel and descriptive statistics generated.

**Results:** 20 (11 male, 9 female) participants with heterogenous solid tumours were recruited. 55% had metastatic cancer. Median age was 66 (range 40–81). Median Eastern Cooperative Oncology Group performance status was 1 (range 0–2). OH was demonstrated in 3 of 20 (15%). No participant with OH reported postural symptoms on standing. 1 (5%) met the criteria for persistent OH. The median number of autonomic symptoms was 7 (range 1–17). Participants with OH described 6, 8 and 16 symptoms respectively.

**Conclusions:**

1. Autonomic symptoms lacked sensitivity and specificity for OH.
2. There was a low prevalence of OH in cancer patients with good performance status.
3. Postural BP tests should be considered in routine screening for everyone with advanced metastatic cancer.
4. Further studies should focus on those with ECOG 2–3 & metastatic cancer; standardised BP measures; heart rate variability and stroke volume.

**Abstract number:** P2-062  
**Abstract type:** Poster

## Comparative Study of Palliative Sedation at the End of Life in the Hospital vs. Palliative Home Care Unit

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**Background:** The clinical practice of palliative sedation (PS) at the end of life is based on clinical guidelines and recommendations that depend on the resources available at home or in the hospital.

**Aim:**

-To describe the profile of cancer patient receiving PS, drugs and doses used and the time from the PS to the end of life, and differences by location.

-To describe the drugs used for PS at the end of life, the reached doses and the duration of sedation

**Methods:**

- **Type of Study:** Longitudinal, retrospective, comparative.

- **Study population:** Patients who died during admission in Medical Oncology Department admitted in conventional hospitalisation or by the Home Care Unit in the Instituto Valenciano de Oncología, Valencia (Spain)..

- **Inclusion criteria:** Patients who received palliative sedation at the end of life during the year 2,013

**Results:** 343 patient who died were recorded, 212 of them received PS; 151 in the hospital and 61 patients at home. The average age was 61 years. 112 patients were women. The most common primary tumors were gastrointestinal (41), breast (39), genitourinary (32) and lung (32); all of them at stage IV. The mean from the last antitumor treatment to death was 21 days. Common refractory symptoms were: delirium (37%); dyspnea (33%) and pain (29%). The drug used was Midazolam in 190 cases. The route of administration was intravenous in 145 patients. Most patients required more than 45 mg / day (53%). 80% of the patients died within 48 hours after starting the PS.

**Conclusions and discussion:** Statistically significant differences found between hospital and home in the administration route and doses can be explained by different clinical management of the patient and the procedures used. However, the results in both groups were similar in sociodemographic and pathological patient profile and time from sedation to death This is the first comparative study carried out in our region.

**Abstract number:** P2-063  
**Abstract type:** Poster

## Correlation of Distress Score with Edmonton Symptom Assessment Scale (ESAS) Score in Patients Referred to Palliative Care: A Prospective Correlational Study

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**Background:** Distress is a multifactorial unpleasant emotional state that may affect how one feels, thinks, and acts as per National Comprehensive Cancer Network (NCCN), and includes feelings of unease, sadness, worry, anger, helplessness and guilt. Patients with cancer have some distress at some point of time. The Distress Thermometer is a tool that can be used to assess distress; it is postulated that it's correlation with ESAS will help us identify Factors causing distress and thus intervene at the appropriate time.

**Aims:** Assessment of Patient's Distress And its Correlation with ESAS Score.

**Methods:** English Version of NCCN DISTRESS THERMOMETER (available tool for measuring Distress) was translated in MARATHI and HINDI. This Scale was served to total of 40 referred patients, along with the ESAS scale (symptom burden), at first visit. Data was collected and analysed using SPSS. We Categorised the distress score into- none(0), mild(1–3), moderate(4–7) and severe(8–10) similar to ESAS Scale.

**Results:** Mean distress score was found to be 5.32. In patients with Mild distress, Negative correlation was found between symptoms and distress. In Moderate distress, Positive correlation was found with ESAS symptoms- Pain, Breathlessness, loss of appetite and loss of sleep, in descending frequency. While in Severe distress, Positive correlation with ESAS- Anxiety, Fatigue, nausea, pain in descending frequency was observed. Other factors in distress scale are not addressed with ESAS (spiritual, emotional, practical and physical).

**Conclusion:** Our data suggest that we cannot rely totally on ESAS symptoms for determining distress. Other factors (problems) should also be taken into consideration. Timely diagnosis and Proper intervention for problems would help to alleviate the distress.

**Abstract number:** P2-064  
**Abstract type:** Poster

## Subcutaneous Route in Palliative Situation: Between Practices and Recommendations. Survey among French Palliative Care Units in 2011

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**Background:** Subcutaneous route is a standard practice in palliative situations, because it is simple, minimally invasive and possible when oral and intravenous administrations are no longer an option. However, in order to provide relief from many symptoms to dying patients, the subcutaneous use of drugs is often without pharmaceutical authorisation application.

**Aims:** This case study focuses on various level of scientific evidences of the molecules used subcutaneously and determines real practice experience of those that turns out to be the most effective ones in palliative care.

**Method:** This is a descriptive and multicenter study. First, 12 molecules were chosen through a pre-study that was carried on with the help of 5 physicians in the field of palliative care.

Then a survey was carried on among practitioners and nurses from the 110 palliative care units of France, to collect data regarding the use and side effects of the 12 pre-selected molecules.

**Results and discussion:** We received answers from 38 physicians and 31 nurses. Physicians have worked in palliative care units for 11 years in average. 19 of them were in a management position. Prevalence of patients that benefits from subcutaneous perfusion was of 18%. Haloperidol, methylprednisolone, furosemide, clonazepam and metoclopramide were prescribed by at least 30 physicians and considered as the most effective ones. No molecule has been seen as inefficient. Haloperidol, methylprednisolone, clonazepam and amitriptyline were prescribed to get 3 specific pharmacological effects. All molecules were mainly use discontinuously except from sodium valproate and clonazepam. The main local side effects were induration/oedema/redness/paleness, occurring more frequently in case of discontinuous injection and pain in continuous administration.

**Conclusion:** This study brings out the potential need for a specific pharmaceutical study that would focus on these 5 molecules in order to increase their level of scientific evidence.

**Abstract number:** P2-065  
**Abstract type:** Poster

## IV Antibiotic Use in Hospice Care

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The use of IV antibiotics differs from hospice to hospice in the E London and Essex areas of UK. There is little research on IV antibiotics and their use/place in palliative and EOL care in hospices. A snapshot of IV antibiotic use in 10 local hospices was gained via an 11 question survey emailed to hospice medical directors. The survey was a mixture of multi-choice questions and free-text.

**Results:** The response rate was high (8/10 responded). There was some correlation between the size of the hospices and the tendency to use IV antibiotics: the larger hospices (>20 beds) all used IV antibiotics several times per month or several times per week. Smaller hospices tended to use IV antibiotics less frequently with one small hospice never using them at all. Reported challenges of using IV antibiotics were:

- the training and continuing competency of staff to prescribe and administer IVs especially in units with low frequency of IV antibiotic use

- having non-resident doctors on call so IV antibiotic regimes had to be achievable within working hours

- knowing which patients would likely benefit

All units who used IV antibiotics agreed that their use had increased over the last 5 years.

There were polarised views: from thinking IV antibiotics rarely add benefit to a patients care to feeling that it is essential that hospices offer IVs to maximise active holistic care and lift the stigma of the hospice being the place you only go to die.

**Conclusions:** This small survey suggests that even in a small area there is a lot of variation between hospices in the use of IV antibiotics. The trend is for increasing antibiotic use: patients and families expect that hospices can deliver this. There is very little available evidence to show useful IV antibiotics are in the palliative population. In the short term, a larger survey of IV antibiotic practice is planned. In the longer term we need larger scale research into the outcomes of using IV antibiotics in palliative care.

**Abstract number:** P2-066  
**Abstract type:** Poster

## Saudi Experience of Using Neuroleptics to Treat Delirium in Dying Cancer Patients

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**Background:** Delirium is a neuropsychiatric problem encountered in terminally ill cancer patients and treated with neuroleptics. However, prescribing patterns are believed to substantially vary among health professionals, limiting potential for benchmarking. The aim is to determine the pattern of prescribing neuroleptic for treating agitated delirium in cancer patients dying in a tertiary palliative care unit in Saudi Arabia.

**Method:** Medical records of adults with advanced cancer who died in a palliative care unit over a 23 months period were reviewed. In addition to patients' demographics, data collection included the pattern of neuroleptic prescribing for the treatment of agitated delirium in the last week of life. The study was approved by the institution review board.

**Results:** For the 271 patients included (57.6% females), the median age was 54 years. All patients had either metastatic (90%) or locally extensive (10%) disease. While 62% of patients were on regular neuroleptics, only 63% of these were prescribed rescue doses as well. The regular neuroleptics included haloperidol (88.7%), levomepromazine (2.4%) or both (8.9%). All neuroleptics were administered via parenteral route. On average, the maximum daily doses used of regular neuroleptics were 4 mg for haloperidol and 15 mg for levomepromazine. For 82.3% of patients on regular haloperidol, the drug was administered until death. Patients with brain metastases were less likely to be on regular neuroleptics (P = 0.001).

**Conclusions:** Haloperidol is the drug of first choice to treat the common problem of agitated delirium in patients dying with advanced cancer in our tertiary palliative care unit. The generally low doses of haloperidol and the fact that majority of patients continued to receive the drug until the time of death may support its effectiveness and safety for use in this clinical scenario. Prescribing rescue doses for patients who require regular neuroleptics is suboptimal and needs to be reinforced.

**Abstract number:** P2-067

**Abstract type:** Poster

## Is Re-irradiation a Viable Option in Metastatic Spinal Cord Compression?

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**Introduction:** Metastatic spinal cord compression (MSCC) is a devastating and frequent event for patients with cancer. The majority of the patients has a short life-expectancy and is treated with short-course palliative radiotherapy only. Short course palliative radiotherapy has been shown to be effective in maintaining neurological function. Historically, a selected group of patients has been treated with re-irradiation of a previously involved part of the spine. The usefulness of re-irradiation might be compromised by radiation dose limiting toxicity e.g. myelopathy.

**Aim:** To investigate the frequency of patients being re-irradiated because of MSCC or impeding MSCC in a previous irradiated field. Secondly, we wanted to record their time of survival after secondary course of radiation.

**Methods:** All patients treated by the indication of MSCC or impeding MSCC were identified using treatment allocation codes in our treatment planning software. Information of patients' primary cancer diagnosis and demographic data were obtained from patient charts.

**Results:** From 2010 until 2012 1597 patients were treated for MSCC or impeding MSCC at our tertiary cancer facility. Out of these thirty-three patients received re-irradiation. Patients mean age were 63 years (18–84) with 14 females and 19 males. The primary cancer diagnoses were prostate- (8), lung- (5) and colorectal cancer (4). Median survival was 122 days (range: 2–1148 days) after start of secondary radiotherapy. Three patients were still alive at analysis, with follow-up of 619–1172 days.

**Conclusion:** A selected group of cancer patients with progression of MSCC have a surprisingly long survival after their secondary course of radiotherapy. Therefore, maintaining neurological function is of outmost importance during the patient's remaining lifetime and re-irradiation could be an option when considering the risk of radiation induced myelopathy.

**Abstract number:** P2-068

**Abstract type:** Poster

## Use of Acetazolamide as Palliative Treatment of Malign Intracranial Hypertension

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**Objective:** Knowing therapeutic utility of acetazolamide in malignant intracranial hypertension as adjuvant to corticosteroids treatment.

**Material and methods:** Descriptive, retrospective and multi-center study of a number of cases collected between 1<sup>st</sup> of January and 1<sup>st</sup> of November of 2012, by three palliative care teams dependent of Primary Care.

Following variables were collected, age, gender, intracranial hypertension causing pathology, symptomatic treatment taken, reason of using and doses of acetazolamide, treatment results, duration of effects after treatment.

**Results:** The number of cases comprises 7 patients, five women and 2 men, age range between 51 and 80. One of them suffered a nervous central system primary tumor, the rest of patients suffered metastases from other tumors (3 lung tumors, 2 breast tumors, and one cervix tumor). Clinic was varied, for every case symptomatic treatment based on dexamethasone, with doses between 4 mg/24 h and 32 mg/24 h, was initiated. In all of seven cases dexamethasone secondary effects (irritability, insomnia and agitation) forced to reduce the doses. In order to avoid clinic from returning acetazolamide was added to reduce cerebral edema. All seven experienced realistic symptomatic improvement. Beneficial effects lasted from 15 to 60 days, depending of each patient, until illness progression forced to take other therapeutic measures.

**Conclusions:**

- Acetazolamide is a known drug in cerebral edema treatment.
- In a number of cases the clinical benefits managing malignant intracranial hypertension are realistic
- Allows a less known therapeutic option for this clinical situation, as adjuvant
- Acetazolamide allows to reduce corticosteroids doses and secondary effects
- Deep studies in order to prove acetazolamide clinical utility are pending.

**Abstract number:** P2-069

**Abstract type:** Poster

## Off-label Use of Drugs in Palliative Cares

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**Introduction:** Off-label use of some medicines is enshrined in Spanish "Real Decreto 1015/2009"; this use will be exceptional, being doctor's responsibility to inform the patient and obtain consent. Off-label use of medicines is a usual practice in palliative cares, for both symptomatic control and administration route.

**Objective:** Describe which medicines, of those used in palliative cares, are used off-label.

**Methodology:** We analysed palliative care most used medicines, from several sources:

1. Those included in the list of essential medicines for palliative cares, published by WHO and IAHPC.
2. Those existing in the medical kits of three palliative cares teams of our community
3. Those proposed in Manual Symptoms Control in advanced and terminal cancer patients (Porta Sales et al ICO).

**Results:**

- Drugs whose data sheet doesn't collect subcutaneous administration indications: Furosemide, haloperidol, chlorpromazine, N-Butilbormuro Hyoscine, midazolam, diclofenac, levopromacina, metoclopramide.
- Drugs that doesn't have neuropathic pain indication approved: topiramato, clonacepam, oxcarbazepina, baclofeno, venlafaxina, carbamazepina.
- Other not collected in data sheet situations:
  - Dexametasona :Astenia – Anorexia
  - Clorpromacina : Hiccup
  - Midazolam : Home Sedation
  - Metilfenidato :Astenia , Drowsiness caused by opioids
  - Difenhidramina : Vomiting
  - Morfina inyectable : Dyspnea
- Topically
  - Transdermal Fentanyl : Dyspnea
  - Octreotida : Intestinal occlusion
  - Oral fentanyl citrate: Breakthrough pain without opioid treatment based
- Lorazepam sublingual
- Ondasetron: Prurito
- Acetazolamida: Brain edema by malignant intracranial hypertension

**Conclusions:** Lots of the medicines which are used in palliative cares are used in off-label situations. This situation is regulated by the Spanish legislation and must be known by the prescribing doctor. Most times off-label use of drugs is supported by scientific evidences.

**Abstract number:** P2-070

**Abstract type:** Poster

## Phenobarbital a Better Drug for Palliative Sedation in Homecare?

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**Background:** The prevalence of palliative sedation for refractory symptoms in terminal patients at home is 6% in our centre. Midazolam is commonly used for palliative sedation but insufficient sedation and tolerance to midazolam are common problems. Due to these problems phenobarbital was introduced in our centre and we set up a titration scheme. As we used phenobarbital more frequently, we noticed that the number of awakenings decreased. The greatest difference between these two drugs is the T½: phenobarbital 24–48h and midazolam 2–5h. This difference has important implications in the clinical use and in the setting up of a titration scheme.

**Aim:** To evaluate the use of our titration scheme of phenobarbital subcutaneous (SC) on time to deep sedation and stability of sedation.

**Method:** We performed an observational study, including 14 patients, using phenobarbital for sedation. Evaluation of the sedation depth was made using the Richmond Agitation Sedation Scale (RASS). The starting dose phenobarbital was 27mg/h. Every 3h (peak dose of the drug used SC) the dose was increased until RASS -4 or -5 was reached.

**Results:** Mean time to deep sedation was 7h (1,5h–17h). The best result (less time to deep sedation) was achieved when the nurse used sufficient bolus dose in the loading up period (100mg–400mg, mean bolus dose=250mg). Mean drug dose was 92,3mg/h (50mg/h–140mg/h). Once sedation depth -3 or more was reached there were no more awakenings.

**Conclusion:** Phenobarbital SC used in a titration scheme is a very useful drug for deep sedation in home care. Stable and deep sedation was achieved, in some cases the time to deep sedation was too long. Based on these results we adapted our scheme by skipping intermediate steps and by giving more systematically bolus doses. In order to evaluate the phenobarbital titration scheme and compare the results to the standard use of midazolam, we are setting up a multicentre prospective study in Flanders.

There was no funding.

**Abstract number:** P2-071

**Abstract type:** Poster

## Prospective Study of Changes in Patient Characteristics in Persons with Intellectual Disabilities at the End-of-Life

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**Background:** According to the definition of the WHO, early identification of physical, psychosocial and spiritual problems is an important aspect of palliative care. Professional caregivers of people with intellectual disabilities (ID) experience many barriers in the identification of these problems. Data on the problems people with ID encounter and the needs they have at the end-of-life are scarce.

**Aims:** In the present study we aim to describe the changes in patient characteristics of patients with ID in the at the end-of-life in a 5 month follow up. Characteristics include activities of daily living (ADL), mobility, comorbidity and symptoms.

**Methods:** A cohort of 150 patients with ID is currently prospectively followed for 10 months. Patients were selected by the physician through a negative answer on the Surprise Question. Physicians and daily caregivers fill in questionnaires at T0, T1 (after 5 months) and T2 (after 10 months). We use the Barthel-index to measure ADL, the Cumulative Illness Rating Scale to measure comorbidity and the Edmonton Symptom Assessment Scale to measure symptoms.

**Results:** T1 is currently in progress and will be completed for the start of the conference.

Therefore, no results are yet available. Results of changes in patient characteristics will be presented at the conference. We are specifically interested in describing the mutual relationships between characteristics, for example the relationship between changes in daily functioning (ADL and mobility) and changes in health status (comorbidity and symptoms).

**Conclusion/discussion:** Because of the lack of data this study will be the first to describe characteristics of patients with ID at the end of life in a prospective manner. The results will generate more insight in the problems and needs of people with ID in this phase of life and will thereby contribute to the quality of palliative care in this population.



Abstract number: P2-072  
Abstract type: Poster

### Effects and Meaning of Music Therapy at the End of Life

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**Background and research aims:** Music therapy, amongst other complementary therapies such as creative therapies, aromatherapy, manual therapies or mind-body therapies is widely used in hospice and palliative care. Aim of this study was to explore the (therapeutic) effects and significance of complementary therapies, especially music therapy, for seriously and terminally ill people at the end of life.

**Study design and methods:** Elements of Grounded Theory and Intuitive Inquiry served as a methodological framework for this qualitative explorative study. A total of twenty multi perspective, qualitative interviews were conducted with managers (n=7), complementary practitioners (n=8) and doctors (n=5) in six German inpatient hospices. There were also focus groups (n=6) with multi-professional team members. Interviews and focus groups were tape-recorded, transcribed verbatim and analysed using Grounded Theory methods.

**Results:** Empirical data shows that music therapy does not only effect physical levels (e.g. decrease of pain and changed pain perception) but also psychological, social and spiritual levels. In the course of an illness not only physiological, but in particular emotional, social or spiritual parts of an individual get hurt or become separated. Multidisciplinary palliative care staff report, that music therapy plays an essential part in reintegrating these separated parts into the individual biography during the dying process.

**Conclusion:** Dying can be understood as a healthy process (of life), which allows the individual to reintegrate separated parts in the biography. To support the dying in these processes of reintegration it needs therapies respectively therapists, which address and respond to bio-psycho-social and spiritual levels. Music therapy plays an important role in the dying process, because of its non-verbal nature and its potential to respond to the individual (needs of a) biography of a person.

## Assessment and measurement tools

Abstract number: P2-073  
Abstract type: Poster

### Validation of an Arabic Questionnaire for Symptom Assessment

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**Background:** Arabic speaking minorities are distributed worldwide. This study aims at validating an Arabic self-administered (SA) tool for assessing the severity of common symptoms among palliative care (PC) patients.

#### Objectives:

1. To test the validity of the Arabic Questionnaire for Symptom Assessment (AQSA) as a SA tool for assessing eleven symptoms among PC patients.
2. To test the validity of AQSA when completed by a proxy.

**Methods:** AQSA is a one page tool for assessing severity of 11 symptoms on a 0–10 numeric scale. The tool was reviewed by 3 external PC experts. Symptom scores on the SA AQSA were compared to scores obtained through interviews with patients. The same procedure was repeated with patients' sitters to explore the validity of using the tool for symptom assessment by proxy. Four centers from 2 countries participated in the study. The statistical analysis involved mainly correlation coefficients, with the level of significance being set at  $p < 0.05$ .

**Results:** The study involved 107 pairs with a mean age of 46.3 years (females 59.8%) for patients and 35.9 years (females 65.7%) for sitters. The correlation coefficient ( $r$ ) for agreement between SA and interview-based scores on AQSA for patients ranged from 0.65 ( $p < 0.0001$ ) for drowsiness to 0.86

( $p < 0.0001$ ) for pain. For sitters, the correlation between SA and interview-based AQSA scores ranged from  $r = 0.73$  ( $p < 0.0001$ ) for insomnia to  $r = 0.90$  ( $p < 0.0001$ ) for shortness of breath. The SA AQSA showed positive correlation between sitters and patients scores, with  $r$  ranging from 0.28 ( $p = 0.004$ ) for depression, to 0.62 ( $p < 0.0001$ ) for vomiting.

**Conclusions:** The strong positive correlation between SA and interview-based AQSA indicates that the former is a valid tool for assessing the severity of the listed symptoms. When the SA AQSA is used by proxy it showed moderate to strong positive correlation with patients' actual scores for most of the symptoms.

Abstract number: P2-074  
Abstract type: Poster

### A Qualitative Study to Elicit the Views of Patients about their Experience of Completing an Holistic Needs Assessment Tool, the Sheffield Profile for Assessment and Referral for Care (SPARC): A Qualitative Study Embedded in a RCT

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**Background:** This is a qualitative study embedded in a randomised controlled trial, to elicit the views of trial participants about their experience of completing a multidimensional holistic needs assessment tool; SPARC. The results of this trial were counter-intuitive leading to concerns about the methodology and raising questions about the concept of holistic needs assessment in a supportive and palliative care service.

**Methods:** As part of a process evaluation, semi-structured interviews were undertaken during a randomised controlled trial with a sub-group of patients (n=33). All participants were interviewed after they had completed the study. The interview schedule was designed to provide a description of patients' views about their experience of completing the SPARC questionnaire, in particular; how they found completing SPARC; what they thought about the SPARC questions; had anything changed because of filling in SPARC; and whether or not they felt that completing SPARC resulted in any actions being taken. Interviews were digitally recorded and transcribed verbatim and analysed using the framework analysis approach.

**Results:** Most patients interviewed (30/33), found SPARC either quite easy to complete, fairly straightforward, simple or had no problems in completing it. Only a small number of participants found questions on SPARC 'too sensitive or upsetting'. Interestingly, a crucial finding in the context of the trial, a surprisingly large proportion of patients interviewed [30/33] did not experience or report any noticeable change, or beneficial effects after completing SPARC.

**Conclusions:** Overall, participants considered SPARC an acceptable and relevant tool for the clinical assessment of supportive and palliative care needs. This qualitative study would help in the interpretation of the outcome results, and provides useful insights into how SPARC might be used in practice.

Abstract number: P2-075  
Abstract type: Poster

### Translation and Cultural Adaptation of the Integrated Palliative Care Outcome Scale (IPOS) to the Portuguese Population

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**Background:** The Integrated Palliative care Outcome Scale (IPOS) is a patient reported outcome measure resulting from the merge of two previously existing measures: the Palliative care Outcome Scale and the Palliative care Outcome Scale-Symptoms. IPOS was developed at the request of several clinicians wanting a more user-friendly measure for clinical practice.

**Aim:** To translate and cultural adapt the original English IPOS into Portuguese.

**Methods:** 2 independent native Portuguese speaking translators, 1 clinical and 1 non-clinical, both blind to the original English IPOS created 2 Portuguese versions. A consensus Portuguese version was developed by 2 native Portuguese speaking independent reviewers not blind to the original IPOS. This consensus version was sent to 2 other independent native Portuguese speaking translators, also blind to the original English IPOS, who back translated it into English. A second Portuguese consensus version was developed by the same reviewers. 3 clinical revisions were performed by 1 specialist palliative care doctor, 1 specialist palliative care nurse and 1 non-clinical researcher – all native Portuguese. A final Portuguese version was created.

**Results:** There were grammatical and content differences in the first translation stage, in the items/questions text as well as in the response categories. These were resolved by discussion by both reviewers. There were also differences in the backward translation, namely verb tenses and the use of synonyms rather than the direct translation of words. These were resolved by discussion by the same reviewers.

The clinical revisions flagged differences in verb tenses in 3 items. Those were discussed and changes were made to create the final version.

**Conclusion:** We created a Portuguese IPOS, now ready to be tested regarding content validity, acceptability, clinical applicability, reliability, internal consistency, construct validity and sensitivity to change.

**Funding:** Calouste Gulbenkian Foundation



**Abstract number:** P2-076

**Abstract type:** Poster

## Independent Validation of the Modified Prognosis Palliative Care Study (PiPS) Predictor Models throughout Three Palliative Care Settings

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**Background:** Accurate prognostic information in a palliative care setting is needed for patients to make decisions and set goals and priorities. The instrument, the Prognosis Palliative care Study (PiPS) predictor models, was presented in 2011, but has not yet been fully validated by other research teams.

**Aims:** The primary aim of this study is to examine the accuracy and to validate the modified PiPS (using physician-proxy ratings of mental status instead of patient interviews) in 3 palliative care settings: palliative care units, hospital-based palliative care teams and home-based palliative care services.

**Methods:** This multicenter prospective cohort study was conducted in 58 palliative care services including 16 palliative care units, 19 hospital-based palliative care teams and 23 home-based palliative care services in Japan from September 2012 through April 2014.

**Results:** A total of 2425 subjects were recruited. Due to lack of follow up and missing variables (principally blood examination data), we obtained a total of 2202 and 1385 analysable data for the modified PiPS-A and PiPS-B, respectively. In all palliative care settings, both the modified PiPS-A and PiPS-B identified 3 risk groups with different survival rates ( $P < 0.001$ ). The absolute agreement ranged from 56 to 60% in the PiPS A model and 60% to 63% in the PiPS B model.

**Conclusion:** The modified PiPS was successfully validated and can be useful in palliative care units, hospital-based palliative care teams, and home-based palliative care services.

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**Abstract type:** Poster

## Supportive & Palliative Care Indicators Tool (SPiCT): Transforming Identification of Patients for Palliative Care Worldwide

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**Background:** Access to palliative care for people worldwide is a healthcare priority. This requires effective ways of identifying patients for palliative care. People at risk of deteriorating and dying often go unrecognised particularly if they have non-malignant disease. Tools designed to predict mortality from individual conditions or manage access to specialist palliative care services do not work well in day to day clinical practice.

**Design:** SPiCT consists of evidence-informed clinical indicators in a one page guide to help GPs, hospital doctors and other professionals to identify patients. Evaluation in clinical practice demonstrated SPiCT's face validity and ability to help teams identify patients at risk of deteriorating and dying. Initial and ongoing development includes web-based dissemination and refinement through a growing network of online, SPiCT Collaborators.

**Result:** In 12 months (2013–14), the SPiCT website had 6080 visits. Registrations to download SPiCT are growing: UK 600 and international 400- Europe, Australia, New Zealand, USA, Canada, S America and Africa. Translations into French, German and Spanish are building non-English speaking SPiCT communities. An online survey of 70 UK and international users in Oct 2014, rated key aspects of SPiCT highly: available on a single page (89%), clinical indicators (93%), community, hospital and hospice settings (81%), promotes early, integrated palliative care (83%). It's clear, credible and can be used in all care settings.

**Conclusion:** The SPiCT should continue to be developed collaboratively by and with individual professionals, multi-disciplinary teams, health service managers, educators, researchers and service users. It is a practical guide to help us identify many more people who stand to benefit from supportive and palliative care. We will present the SPiCT and show what it offers the palliative care community. The SPiCT ([www.spict.org.uk](http://www.spict.org.uk)) is a valued tool internationally.

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## The Patient Dignity Inventory for Cancer Patients, Families and Clinicians in the Home Palliative Care

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**Aims:** The Patient Dignity Inventory (PDI) is a tool based on the empirical model of dignity in the terminally ill (Chochinov and colleagues). It evaluates the different aspects of patients' experience nears the end of life and can be used like a guide for the clinicians to comprehend the patients' dignity. It was validated in Italian on patients with solid and hematological cancers on active treatments. We used the PDI with cancer patients in home palliative care. The purposes were: – to evaluate the patients' sense of dignity; – to monitor the dignity during home palliative care; – to improve the communication between clinicians, patients and family; – to facilitate the on-work education of clinicians.

**Methods and approach:** The project involved thirteen nurses. It consisted of three parts: 1. workshop conducted by a psychologist who attended the Dignity Therapy Workshop, in order to give information about the model of dignity and the administration of PDI;

2. application of PDI in clinical practice;

3. sharing the observations twice a month by clinic audit.

We used this tool in 50 cases and we attended the 12 meeting to discuss benefits and difficulties.

**Lessons learned:** The PDI were used after two-three meetings with patients because during

the first consultation it was most necessary to evaluate patients' personality. To share the PDI data with families improved the perception of their competence and role in home care. It improved the communication with patients and family. Some questions promoted the cognitive and emotional processing of the sense of burden to others, the loss of independence and the loss of the role in family and society.

**Conclusions:** We used the PDI as a screening tool, in order to organise the personalised project for patients and to evaluate the emotions and thoughts of the clinicians.

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**Abstract type:** Poster

## Recognizing the Need for Palliative Care in People with ID: The Perspective of ID-physicians

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**Background:** A trend of longevity is seen in people with intellectual disabilities (ID). Because of this longevity more people with ID are suffering from cancer or other life-threatening illnesses and therefore are in need for palliative care. In general, it is difficult to recognise the need for palliative care and in people with ID it even more difficult, due to problems with communication. Timely recognition, however, is essential for adequate provision and planning of palliative care which leads to a better quality of life.

**Aims:** The aim of this study is to investigate how ID-physicians recognise people with ID who are in need for palliative care.

**Methods:** A qualitative interview study was conducted among 10 ID-physicians in the Netherlands.

**Results:** ID-physicians describe the recognition of the need for palliative care mostly as a process in which multiple signals and moments on which decisions have to be made, accumulate and raise a certain awareness. This awareness makes them take a closer look at the client. The conclusion of this closer look may be that a patient has palliative care needs. The signals can be noticed directly by the ID-physicians, but also by clients, professional caregivers and family caregivers. Facilitators for the recognition of palliative care are, for example, good collaboration and communication between all the caregivers involved and the frequency of the contact between the physician and the patient.

**Conclusions / Discussion:** Recognition of the need for palliative care can be a moment, but is mostly described by ID-physicians as a process during which multiple signals accumulate and raise awareness. In addition to these findings, it would be worthwhile to examine the perspective of professional caregivers and family caregivers on this process. More insight in the recognition of the need for palliative care is crucial for early identification, adequate planning and provision of palliative care which leads to a better quality of life.

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**Abstract type:** Poster

## A Comparison of Faecal Loading and Colon Transit Times in Palliative Patients

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**Background:** Clinical guidelines continue to recommend plain abdominal radiographs as a recommended component of the palliative assessment of constipation. This is despite the fact that this practise is not recommended in the assessment of functional constipation.

**Aims:** This project is aiming to compare the appearance of faecal loading on plain abdominal radiographs against the objective reference of colon transit times. For this work, colon transit times will be calculated according to the number of radio-opaque markers visible after 6 days.

**Methods:** The abdominal radiographs with radio-opaque markers used to measure colon transit times in a study of constipation will be reviewed. This is with the intent of comparing the degree of faecal loading visible and comparing this with other factors which include:

- 1) whether there is inter-observer agreement between the degree of faecal loading;
- 2) whether measured colon transit times and the degree of faecal loading correlate;
- 3) whether patient's self-reported constipation symptoms and the degree of faecal loading visible correlate.

**Results:** To date, abdominal radiographs of colon transit time studies are available for 25 patients, all of whom have a malignancy underlying their referral to palliative care. The radiographs were taken in people who all self-identified themselves as constipated and requiring regular laxatives. Nearly all (n=23) had opened their bowels within the previous 3 days. Colon transit times were deemed slow for 10 of the 25 patients. The correlations are not reported here as the study is still recruiting.

**Conclusion:** The optimal outcome of this study would be to reduce the number of unnecessary investigations that are being ordered for patients in palliative care.

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**Abstract type:** Poster

## Implementing Outcome Measures in Palliative Care: Putting the Evidence into Practice

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**Background:** Measuring palliative care outcomes is widely advocated with little evidence on how best to implement measures into practice. The UK-based Outcome Assessment and Complexity Collaborative (OACC) is implementing outcome measures (OMs) into palliative care practice, and building evidence on how best this can be done.

**Aim:** To apply systematic review recommendations on implementing OMs into clinical practice across palliative care and review results.

**Method:** Systematic review<sup>1</sup> recommends 4 strategies which were undertaken by Quality Improvement Facilitators (QIFs):

- Tailored implementation* using appropriate facilitators tailored to the characteristics of each team
- Educational intervention* prior to implementation on how and when measures are used and suggestions of how they may be integrated into practice
- Timely feedback* of results at both patient and service level
- Use of a facilitator* working alongside clinicians throughout the implementation process to address concerns as they arise

**Results:** OMs were implemented with 9 teams across 6 services. Core components of the intervention were fixed, but local adaptation occurred. Most clinicians are unfamiliar with OMs and question their clinical relevance. Attitudes to use change as benefits become apparent. Resistance is offset by increasing rapport and support from the QIF.

An adjustment phase before main data collection enables teams to consider how best to integrate OMs into practice. Feedback impacts on individual patient management, distribution of team workload, organisational quality improvement and understanding of complexity.

**Conclusions:** The four strategies were successful. Feedback is especially powerful in influencing attitudes towards the use of OMs but implementation needs time, facilitation and encouragement. The role of QIFs throughout implementation process is key to embed OMs into routine practice.

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1 Antunes B et al. *Pal Med* 2014;28(2):158–75

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**Abstract type:** Poster

## The Content Validity and Utility of a Screening Tool to Improve Detection of Problems, Care Provision and Healthcare Access for People with Dementia in Residential Care Homes: The Palliative Care Outcome Scale for Dementia – Screening (POS-DemS)

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**Background:** The global prevalence of dementia is estimated at 44.4 million and expected to increase to 135.5 million by 2050. People with dementia experience untreated problems due to challenges of poor detection. Residential care home staff, many without clinical training, need to detect and communicate resident problems to health providers to access treatment. Screening tools introduced into routine care have the potential to improve care and health provision.

**Aims:** To explore the content validity and develop the utility requirements of a screening tool used to detect and communicate problems to inform care provision.

**Methods:** A qualitative study was conducted in three London care homes using focus groups and in-depth interviews with family and friends, using criterion sampling; and care home staff, GPs and district nurses using maximal variation sampling. Content analysis of verbatim transcripts was conducted.

**Results:** Data from 26 participants resulted in three categories: content validity, utility and processes. Content validity: Comprehensive screening must not be compromised by brevity. Additional dementia-specific items were identified for inclusion and six items combined into three for brevity (hallucinations/delusions, nausea/vomiting, appetite/weight loss). Utility: a routinely implemented tool may improve detection of problems, inform care plans and support integrated working but risks to utility, including problems of reliability, feasibility, recall and tick-box use, must be minimised. Processes: resident need should inform implementation, including flexible use and comprehensive information sourcing, while complementing existing care processes.

**Conclusions:** The use of comprehensive yet brief screening measures, informed by resident need and embedded in care processes, will influence care processes, including detection of problems and improved communication.

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**Abstract type:** Poster

## Moving on – How Do Improved Definitions Impact Predictive Validity of the ECS-CP?

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**Background:** The Edmonton Classification System for Cancer Pain (ECS-CP) has been extensively validated and consists of five pain features: mechanism of pain, incident pain, psychological distress, addictive behavior and cognitive function. Basic research demonstrates the complexity of bone and nerve pain, exposing the oversimplification of

present conventionally accepted pain mechanism classification. Lack of consensus in the diagnosis of neuropathic pain remains a challenge in classifying cancer pain with the NeuPSIG grading system offering the basis for a standardised approach to improve assessment and potentially treatment outcomes. Inter-rater variation in the assessment of incident pain has been identified as a problem and could be improved with refinement of the guidelines.

**Aims:** We hypothesised that the introduction of enhanced definitions for neuropathic and incident pain would improve the predictive validity of these features with regard to time to achieve stable pain control and use of complex analgesic regimens.

**Methods:** 300 advanced cancer patients were recruited from 2 acute care hospitals and a Tertiary Palliative Care Unit. A palliative care specialist completed an ECS-CP for each enrolled patient including grading of neuropathic pain into possible, probable or definite according to NeuPSIG criteria.

**Results:** 231/300 (77%) patients had a pain syndrome. In univariate analysis, age, nociceptive pain, neuropathic pain, incident pain, cognition (normal, impaired) and pain intensity were independently associated with time (days) to stable pain control ( $p < 0.05$ ). In multivariate analysis, age, nociceptive pain, neuropathic pain, incident pain (present, unable to assess) and pain intensity were independently associated with time (days) to stable pain control ( $p < 0.05$ ).

**Conclusion:** Compared with our previous model, psychological distress was not an independent predictor, potentially due to a small sample. Further analysis is required on the study hypothesis.

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**Abstract type:** Poster

## Changes in Pain Classification during the Care Trajectory

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**Background:** The Edmonton Classification System for Cancer Pain (ECS-CP) has been extensively validated and consists of five pain features: mechanism of pain, incident pain, psychological distress, addictive behavior and cognitive function. Validation to date has been based on the initial ECS-CP. This does not take into account ongoing clinical evaluation and disease related changes which may alter classification. How much variation in classification can occur over time has not been explored.

**Aims:** We hypothesised that some classification features would change over time mostly related to fewer features classified as "insufficient information" and cognitive decline.

**Methods:** 300 advanced cancer patients were recruited from 2 acute care hospitals and a Tertiary Palliative Care Unit (TPCU). A palliative care specialist completed an initial ECS-CP, followed by a weekly ECS-CP evaluation and then a final ECS-CP at study completion.

**Results:** The TPCU had the most ECS-CP changes over time, with the highest frequency for psychological distress (46/98, 47%). Across all sites, pain mechanism and addictive behavior were the most stable features, with the lowest frequency (17/231, 7%); while cognitive function was the least stable, with the highest frequency of changes (74/213, 32%). The most common changes for incident pain and psychological distress were from "insufficient information" on initial assessment to either absence or presence of a feature; while the most common change for cognitive function was a decline in cognition.

**Conclusion:** Overall the ECS-CP assessments were generally stable over time. In some settings, such as the TPCU, it may be more appropriate to conduct assessments more frequently due to the dynamic status of patients. Similarly, fluctuations in cognition are an expected change and thus should be assessed more frequently.

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**Abstract type:** Poster

## A Symptom Prevalence Study of Outpatients with Chronic Liver Disease

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**Background:** Liver disease is the fifth largest cause of death in the UK and its incidence is increasing. There are few current studies that have examined symptom presence and prevalence in patients with cirrhosis of any cause. Categorising symptom prevalence and severity in this patient group may make a case for collaborative working between hepatology and palliative care teams to improve quality of life in a population with advanced life-limiting disease.

**Aims:** To evaluate symptom prevalence and severity in patients with cirrhosis of any cause, identify factors which determine symptom presence, and evaluate predictors of symptom severity.

**Methods:** Symptom data were collected from patients with cirrhosis who attended a hepatology clinic. Data were collected using a validated version of the Palliative Outcome Scale, the POS-S. Demographic data were also collated.

**Results:** 16 patients expressed interest in taking part but only 10 were recruited due to clinical deterioration. Mean age was 55.8 years (95% CI, 47.79–63.81). 60% of patients had cirrhosis due to alcohol. 70% met criteria for liver transplant on UKELD score. Only 1 was listed. 50% of the study population had significant comorbidity. The median POS-S score within the study population was 14. No patient was symptom free. The most commonly reported symptoms were dyspnoea (100%); weakness (90%) and pain (80%). 70% of the study sample identified additional symptoms. For 5 patients these symptoms were severe. Patients with dyspnoea, weakness and nausea were significantly more likely to have high overall symptom burden.

**Conclusions:** This is the first study to describe symptom prevalence and severity in patients with cirrhosis using the POS-S tool. Both symptom presence and symptom severity were demonstrated in this group, regardless of aetiology of cirrhosis. This study suggests that collaboration between hepatology and palliative care services is appropriate, to optimise organ function while addressing symptom control.

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**Abstract type:** Poster

## Textile-based Monitoring System in Palliative Home Care: An Exploratory Study

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**Background:** Transitions and trajectories are characteristic for acute incidents, yet little research has been devoted to details. By now, portable sensor-based monitoring systems are available to assess vital parameters and to draw conclusions concerning quality of life. Additionally, they allow to derive transition processes in acute incidents.

**Aims and research questions:** The current project intends to utilise innovations in the areas of sensor technology and smart textiles for palliative care. The long-term objective consists of developing solutions for tailored palliative care in the domestic setting. The research questions are as follows: Which parameters can be identified as indicators for critical incidents in patients at the end of life in the scientific literature as well as from the relatives' and experts' point of view? How can a textile-based monitoring system be utilised for detecting critical incidents?

**Methods:** International scientific literature on trajectories and transitions was analysed. Afterwards, interviews with 21 relatives of patients who have died in a palliative care unit were conducted, supplemented by expert interviews concerning the importance and the significance of the results for palliative care.

**Results:** Five key aspects of critical incidents could be identified:

- 1) **fear and insecurity** of relatives with regard to care,
- 2) **dyspnea**: affected persons rarely contact health care institutions,
- 3) reduced or impossible **food intake**,
- 4) **pain**: relatives often do not know how to react and focus on hospitalisation,
- 5) lack of **night sleep** in dying persons and/or relatives.

**Conclusion:** The results reveal differences in grief of relatives, depending on „acute“ or „targeted“ care of the dying person in the palliative care unit. On the basis of these results approaches to a textile-based monitoring system can be derived.

**Abstract number:** P2-087

**Abstract type:** Poster

## Patient-reported Outcome Measures: How Frequently Are they Completed by Patients with Palliative Care Needs?

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**Background:** Determining the outcome of care given to patients is fundamental in any clinical care setting. Patient-Reported Outcome Measures (PROMS) are important to determine the perspective of those receiving the care. However, there can be challenges to achieve this in patients with palliative care needs, for example, patients may feel too unwell, too distressed, or have altered cognition to complete or/and healthcare professionals may gate-keep giving such measures. A systematic review of the use of PROMS revealed that most evidence has been obtained from the outpatient oncology setting.<sup>1</sup> There is little literature to inform us how frequently PROMS are completed in an inpatient palliative care setting.

**Aims:** To determine

- a) how frequently PROMS are completed by patients with palliative care needs during an inpatient stay, and
- b) if not completed, the reasons for non-completion.

**Methods:** A validated questionnaire exploring symptoms and quality of life (St Christopher's Index of Patient Priorities – SKIPP) is given to every patient admitted to two hospices and at intervals during their stay. We are retrospectively collecting data on 200 consecutive admissions to two hospices in the UK to determine how frequently these are completed.

**Results:** Data collection is in progress, but will be fully reported.

**Conclusion:** This will depend on the results that are found.

1. Etkind SN, Daveson BA, Kwok W, Witt J, Bausewein C, Higginson IJ, Murtagh FEM, Capture, transfer and feedback of patient-centered outcomes data in palliative care populations: Does it make a difference? A systematic review. JPSM 2014 in press

**Abstract number:** P2-088

**Abstract type:** Poster

## The Feasibility and Usefulness of the EAPC Basic Dataset in Clinical Practice – A Single Unit Experience

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**Background:** To date systematic research in palliative care has the problem of incomparableness of data due to missing criteria of how to describe study populations. To clarify this matter, the EAPC basic dataset was published in early 2014.

**Aim:** Our first goal was to test the feasibility of this dataset in clinical practice on our Palliative Care Unit. The second aim was to gather more information on our patients and on the many different problems they are faced with during hospitalisation in order to improve our services.

**Methods:** Upon admission the patient and health care provider form of the published dataset and ECOG scales were to be documented from each patient between 01/05/14 to 31/08/14. On day 2 and before dismissal, the symptoms according to the patients form and ECOG were collected, as well. All data were transferred into a database and statistically analysed.

**Results:** In this timeframe, 108 hospitalisations took place at our ward. The number of eligible datasets collected upon admission was 91 (84.3%), on day two 70 (71.4%) and before dismissal 35 (48.6%), respectively. The median age was 68.1 years (36.1–88.9) and there were 41 female and 39 male patients. During their stay, 36 subjects (39.5%) died at our ward. 3 patients had no cancer diagnosis, the rest (96.7%) suffered from cancer. In the cancer population, 88.9% were metastasised, 10.1% had locally advanced cancer. Patients (n=) describing the different symptoms score > 2 at the 3 different timepoints are shown in table 1.

n= %	Pain	Tiredness	Drowsiness	Lack of Appetite	Depression	Wellbeing	Sleep	Constipation	Breath
<b>Admission</b>	39.8	87.5	82.9	69.4	37.5	90.9	44.3	48.8	26.2
<b>Day 2</b>	26.5	82.4	85.3	64.7	39.7	83.8	48.5	41.2	19.1
<b>Dismissal</b>	11.8	70.6	73.2	61.8	32.4	79.4	17.6	23.5	8.8

[Table 1]

**Conclusion:** The collection of this dataset is feasible in clinical practice and provides a lot of useful information for clinicians especially in terms of improving the understanding of the needs of our patients.

**Abstract number:** P2-089

**Abstract type:** Poster

## Changes in Skeletal Muscles of Patients with Breast Cancer before Death

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**Background:** Skeletal muscle wasting is a prognostic indicator of cancer. In patients with lung or gastrointestinal cancers, skeletal muscle mass decreases exponentially during 3 months before death. However, patients with breast cancer have not been examined in this regard.

**Aims:** To assess skeletal muscle wasting in patients with breast cancer during 12 months before death.

**Methods:** This was a retrospective observational study. We examined patients with breast cancer who came for a consultation to the Teikyo University School of Medicine Hospital between April 2006 and December 2013. Of these, we examined 26 patients who died of breast cancer. We quantified the loss and gain in skeletal muscles using computed tomography (CT) images. Statistical analysis was conducted using the chi-square and Student's t-tests.

**Results:** The 26 patients who died of breast cancer had undergone 96 CT scans during the 12 months before death. With consideration of all time points, muscle loss was detected in 34.3% of the intervals between any two scans. The overall frequency of muscle gain was 5.7%, whereas muscle mass was stable in 60.0% of the intervals between any two scans. We compared the average changes in skeletal muscle mass between two equal periods (months 1–6 and 7–12) before death. Muscle mass decreased more during the 6 months immediately before death (95% confidence interval 1.7–8.7; P = 0.0054).

**Conclusion:** Regular skeletal muscles of patients with breast cancer significantly decrease during 6 months before death. However, further research in a larger cohort is warranted.



**Abstract number:** P2-090  
**Abstract type:** Poster

## Palliative Care Needs Assessment in Albania

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**Objective:** Presentation of the current situation of palliative care(PC) in Albania – PC needs, barriers and its future.

**Methodology:** Information and data were collected from the study report – *PC needs assessment in Albania* CITATION Con10 \1 1033 (Connor & Huta, 2010).

**Results:** Based on the current situation of PC results show: PC in Albania is provided only to cancer patients; cancer is the cause of death for approximately 2907 patients/ year; 980 patients receive partial PC; 1927 are provided with PC; 7865 patients diagnosed with a non-cancerous disease require PC but are not provided with this service. Based on this estimation, each year a total of 9792 patient who require PC remain uncovered from this service. Currently in Albania patients have access to opiates. In the ambulatory service the use of opiates is limited because of the opiophobia of GPPC doctors are allowed to prescribe opiates without limit.

This needs assessment highlights the need for staff in PC based on the population number and the epidemiologic data.

**Goals and future plans of the National PC Working Group** – Development of the national PC standards; national PC needs assessment; preparation of a unified curricula for the PC training; development of a strategic plan for the implementation of PC; development and approval of a law for PC; preparation of a national public education program on PC in accordance with the National Cancer Control Plan for Health care providers; Increasing number of home based PC providers; establishing PC services in the major hospitals of the country.

**Recommendations:** Considering the increasing number of patients that require PC, we recommend:

PC available for all patients diagnosed with incurable diseases. Inclusion of PC in the Public Health Services. Inclusion of PC in the education curricula of the medicine, nursing and social work faculties. Monitoring and evaluation of the situation and needs from all PC providers that operate in the entire country.

**Abstract number:** P2-091  
**Abstract type:** Poster

## Do Palliative Care Teams Perform Better than Non-palliative Care Teams in Symptom Control?

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**Introduction:** The effectiveness of different strategies of palliative care provision is little known.

**Objective:** To compare symptom control effectiveness provided by two health care teams: interconsultation palliative care (IPTC) and non-palliative care (NP) in the first 48h from hospital admission.

**Method:** Pragmatic clinical trial carried on 286 consecutive adults inpatients with advanced cancer, admitted in general hospital (IPTC=73 and NP=75) and in oncology hospital (IPTC=53 and NP=87), 2012–2013, with pain  $\geq 4$  (0–10) or at least others two symptoms with intensity  $\geq 4$  (0–10). All were interviewed at admission, 24h and 48h from admission. Symptoms were measured by the Edmonton Symptom Assessment System (ESAS). The endpoints were 2 points reduction of the initial pain or other symptoms scores after 48h from admission, and 20 points reduction of the initial symptom burden score after 48h from admission. Multiple Poisson regression analysis was done to verify the endpoints occurrence.

**Results:** The symptoms burden average scores at admission were moderate and similar in IPTC and NP groups. After 48h from admission, symptom burden improved only in NP group ( $p < 0.001$ , Wilcoxon test). The regression analysis showed relative risk reduction of 2 points in **pain score** ( $RR=2.2$ ;  $p < 0.005$ ), **well-being score** ( $RR=4.6$ ;  $p < 0.01$ ) and **constipation score** ( $RR=3.2$ ;  $p < 0.02$ ) in IPTC group. Relative risk reduction of 2 points in **pain score** ( $RR=0.6$ ;  $p < 0.04$ ) was observed for NP group.

**Conclusion:** These findings highlight that the team's performance in control were similar and the symptoms were poorly controlled after 48h from admission.

**Abstract number:** P2-092  
**Abstract type:** Poster

## A Multidisciplinary Assessment and Follow up Questionnaire of Palliative Sedation: The Experience of Hospice Bentivoglio (Bologna, Italy)

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**Background:** Palliative sedation (PS) is a medical treatment part of continuum of palliative care, used for the control of refractory symptom in patients at the end of life. We created a questionnaire to improve the good clinical practice of PS.

**Aims:** The aim of this study is evaluate the decisional and therapeutic process of PS in a period of one year in our Hospice by a specific tool.

**Methods:** The multidisciplinary questionnaire is composed of four parts about the different aspects of PS: diagnosis of refractory symptom, pharmacological interventions, evaluation of awareness of patients and main caregivers (CG) about clinical situation and PS, follow up during PS with RASS scale. The population is the inpatients of Bentivoglio Hospice. From May 2013 to June 2014 we're leading an observational, non randomised, prospective study on PS in Bentivoglio Hospice, using the questionnaire when PS is evaluated.

**Results:** After the first period of six months 67 of 284 patients dead in our Hospice (23%) received PS. The pre-clinical results show that 66 patients (98,5%) had an advanced tumor, 1 had a pulmonary non-oncological disease (1,5%); 40 patients (60%) had full awareness of their diagnosis, 22 patients (33%) had full awareness of their prognosis (33%). 11 patients (16%) knew the possibility of sedation while in hospice and only one of these patients didn't agree with PS until onset of refractory symptom. Dyspnea was the most frequent refractory symptom (61%). Midazolam was the most common drug prescribed. 57 CG (85%) have been

informed about the possibility of PS during the recovery, 22 CG (33%) asked the PS for their relative. 66 CG (98,5%) agreed to PS when proposed, one patient hadn't a CG.

**Conclusions:** A multidisciplinary questionnaire for assessment and follow up of PS in inpatients hospice leads to a real shared clinical and multidimensional evaluation among professionals, patients and caregivers.

**Abstract number:** P2-093  
**Abstract type:** Poster

## Can Chronic Pain and a Smoking History Contribute to Complexity of Pain Management?

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**Background:** The Edmonton Classification System for Cancer Pain (ECS-CP) has been extensively validated and consists of five pain features: mechanism of pain, incident pain, psychological distress, addictive behavior and cognitive function. In chronic nonmalignant pain, the relationship between psychological distress and pain catastrophising has been well recognised as a complicating factor, highlighting the potential role of a history of opioid treatment for chronic nonmalignant pain as an additional variable to include in the ECS-CP. The positive association between pain severity and smoking also deserves closer examination for inclusion in the ECS-CP guidelines for addictive behavior.

**Aims:** We hypothesised patients with a history of chronic nonmalignant pain and a history of smoking would require a longer time to achieve stable pain control and use more complicated analgesic regimens.

**Methods:** 300 advanced cancer patients were recruited from 3 palliative care sites – 2 acute care hospitals and a Tertiary Palliative Care Unit. A palliative care specialist completed an ECS-CP for each enrolled patient. Routine patient demographics included history of previous opioid use and smoking.

**Results:** 21/300 had a previous history of opioid treatment; 18/21 were evaluable, with an average of 7.5 years of use (SD 7.7). 183/300 had a history of smoking, with an average of 33.9 pack years (SD 22.2) and 154/300 (51%) were current smokers. In a multivariate analysis of patients with a pain syndrome ( $n=231$ ), age, nociceptive pain, neuropathic pain, incident pain (present, unable to assess) and pain intensity were independently associated with time (days) to stable pain control ( $p < 0.05$ ). A history of opioid treatment and current smoking were not statistically significant in the multivariate model.

**Conclusion:** Current smoking and previous opioid use do not appear to be important features in a pain classification system. However, given the small sample further research is warranted.

**Abstract number:** P2-094  
**Abstract type:** Poster

## Symptom Assessment in Advanced Cancer

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**Background:** Advanced cancer patients are polysymptomatic with a median of 11 symptoms. Symptom burden is an important predictor of quality of life. To effectively evaluate and control symptoms, a comprehensive systematic assessment is required at initial consultation and periodically thereafter.

**Aims:**

1. Review the assessment and documentation of 12 common cancer symptoms.
2. Compare an admission template with non-template documentation.

**Methods:** A retrospective medical record review was conducted at a palliative medicine inpatient unit. Consecutive in-patient cancer deaths over a 4 month period were assessed with a data recording form. The comprehensiveness of medical and nursing admission documentation of the 12 study symptoms was evaluated. Descriptive statistics were generated with Apple Numbers.

**Results:** Of 102 medical records reviewed, 93 had cancer. 47% of admissions were template based and 53% non-template. The most commonly recorded symptoms were: pain [91%]; fatigue [81%]; constipation [77%]; dyspnoea [73%]; nausea/vomiting [69%]. The least commonly recorded were the neuropsychological (insomnia [45%]; depression [31%]; anxiety [24%]) and nutritional symptoms (mouth problems [42%]; weight loss [12%]; early satiety [3%]). The mean number of recorded symptoms in the systematic template was 7.5 versus 5 in non-template. In template-based admissions, presence or absence of symptoms was documented, whereas non-template only recorded presence.

**Conclusions:**

1. Systematic admission templates provided a more complete assessment and documentation of symptoms.
2. Neuropsychological and nutritional symptoms were under-evaluated.
3. Selective symptom assessment biases symptom profiles.
4. Further research should evaluate the utility of routine template-based assessments.



**Abstract number:** P2-095  
**Abstract type:** Poster

## QOL Using SEIQoL-DW for Advanced Cancer Patients Receiving Outpatient Palliative Care

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**Aims:** The aim of this study is to clarify the characteristics of the personal QOL for advanced cancer patients for whom treatment is not possible, and to consider support for improving QOL.

**Methods:** The Schedule for the Evaluation of Individual Quality of Life-Direct Weighting (SEIQoL-DW) was implemented on advanced cancer patients receiving outpatient palliative care. The SEIQoL-DW is a methodology that, through a semi-structured interview, extracts 5 areas thought by the patients to be the most important in their lifestyles, and produces a QOL score from the satisfaction level for each level and its weighting overall. We analysed the relationship between the QOL score and the content, satisfaction level, and weighting for each area that the patient thought was important.

**Results:** The study was implemented on 14 subjects (8 patients were undergoing anti-cancer therapy, and 6 patients were not). The average interview time was 13 minutes. The QOL score was  $66.3 \pm 22.5$  ( $58.23 \pm 24.5$  for the anti-cancer therapy group, and  $79.7 \pm 9.8$  for those not receiving treatment). The areas that patients often considered to be important were anti-cancer therapy (6 patients), children (6 patients), spouses (5 patients), housework (5 patients), etc. The patients that considered anti-cancer therapy to be important had a mean satisfaction level for anti-cancer therapy of 34, and a mean weighting of 28%.

**Discussion:** One of the factors underlying the fact that the QOL score for patients undergoing anti-cancer therapy was low, was that despite the satisfaction level for anti-cancer therapy being low, the weighting with respect to lifestyle was high. In order to improve the QOL of patients undergoing anti-cancer therapy, it is necessary to support the increasing of the weighting for areas other than anti-cancer therapy.

**Abstract number:** P2-096  
**Abstract type:** Poster

## Identifying Palliative Care Needs in US Emergency Departments

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**Background:** The American College of Emergency Physicians has recommended that high morbidity and terminally ill patients be identified for palliative and hospice care services in US Emergency Departments (ED). To implement this, we evaluated a palliative care screening tool in the ED of a large, urban hospital where usual treatment and disposition has been resuscitation and ICU admission.

**Methods:** During April and May 2014, 52 potential ICU admissions were screened or retrospectively reviewed for palliative care risk factors using a 7-item screening tool during a convenience sample of ED shifts. Risk factors (RF) included: transfer from nursing home, metastatic cancer, high symptom burden, frequent hospital admissions, end-stage organ failure, cardiac or respiratory arrest, and poor prognosis. Patients were scored as negative (no RF) or positive ( $\geq 1$  RF).

**Results:** Of 52 patients screened, 38/52 (73.1%; 95% CI .60–.83) scored positive and 18/38 (47.3%) of these patients received palliative care consults: 10 were initiated in the ED and 8 in the hospital. Of the 10 palliative care consults performed in the ED, the code status of 9 patients was changed during consultation to "Do Not Resuscitate" (DNR) and 1 remained full code. All 9 DNR patients met ICU admission criteria. Subsequently, 3 were referred to palliative care services and 6 were admitted.

**Conclusion:** Palliative care screening and consultation in the ED are feasible and can impact resuscitative care plans and disposition. It can help coordinate care that is consistent with patient values and may also lead to a reduction in ICU admissions. Further research is needed to quantify the benefits of palliative care screening and consultation on critical care admissions from the ED.

**Abstract number:** P2-097  
**Abstract type:** Poster

## Factors of Essential and Existential Importance at the End of Life – A ZMET Analysis among Patients and Relatives in a Hospice

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Patients received at a hospice are marked by their disease, often holding unpleasant symptoms. Many come from hospitals, where they have experienced a lot of treatment. Also, many have filled out questionnaires and scores for different purposes. In this situation it is difficult to burden the patients with further questionnaires or scores in order to reveal factors of crucial importance at the end of life. We wanted to elucidate this in a feasibility study. We performed a ZMET analysis according to Zaltmann (ZMET = Zaltmann's Metaphor Elicitation Technique). Ten patients and 3 relatives were provided with a digital camera. After instruction and consent they were asked to snap shot situations, activities and other matters of importance from daily life in hospice. After a few days, the participants were invited to a dialog over the pictures to elicit deeper thoughts and emotions through reflections over motives, situations and other subjects pictured in the photos. All patients had been in the hospice for more than 1 week. The study showed that the ZMET technique is suitable for these rather weak and burdened patients and relatives. Generally, they saw the participation as an appreciation. Furthermore, the study revealed the importance of the possibility of being together with the family, friends and relatives as much as wanted. The nearness to nature was extremely important due to spectacular sights and the calmness and consistency of views outside the windows. Furthermore, the possibility to furnish the room in their own way, with own paintings, pets and artifacts was important as was the daily morning song and worship. The possibility of food choices was appreciated, as was social events like the "wednesday bar", musical events, the quality of paintings and arts in hospice. Photos together with the associated reflections and stories will be presented.

**Abstract number:** P2-098  
**Abstract type:** Poster

## Effects of Family Caregiver's Anxiety and Depression on Retrospective Ratings of Quality of Dying and Death (QoDD) of their Loved Ones

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**Background:** In studies using informal caregivers' (IC) of patients in palliative care (PC) it has to be ensured that findings are not influenced by factors such as mental disorders. This study aims to describe the influence of anxiety and depression on bereaved IC' retrospective ratings of Quality of Dying and Death (QoDD) of their loved ones.

**Methods:** IC of deceased patients from two German PC units (Erlangen took part in a validation study of the QoDD at the earliest in the fourth week after the patient's death. Depressive and panic disorders were assessed via the Patient Health Questionnaire (PHQ). Group comparisons (Chi<sup>2</sup>, T-test; significance level  $p < 0.05$ ) analysed whether IC with versus without depressive or panic disorder differ in their estimates of quality of dying and death (QoDD) of their deceased loved ones.

**Results:** A total of 226 IC participated during August 2012 to December 2013. The mean age of participants was 55.5 years (range 22.3 – 85.0 years) with 61.1% female. The PHQ of 221 participants resulted in 19 (8.6%) with major, 30 (13.6%) with other depressive syndrome and 77.8% ( $n=172$ ) without depressive disorders. No difference between female and male participants concerning the incidence of depression ( $p < .519$ , Chi<sup>2</sup>). Two (0.9%) participants were screened positively for both panic and for major depressive disorders. Participants with vs. without mental disorder showed no differences in interview burden or duration. The T-test for the group of participants with major or other depression syndromes ( $n=35$ ) vs. participants ( $n=137$ ) with no signs of depression presented no significant differences in the mean total QoDD scores ( $p < .343$ ).

**Conclusions:** ICs' estimates on QoDD of their significant others are not influenced by mental disorders. Therefore bereaved IC are well able to participate in PC research a few weeks post-loss.

**Abstract number:** P2-099  
**Abstract type:** Poster

## Associated with Quality of Life and Depression among Patients with Hematopoietic Stem Cell Transplantation

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**Background:** Treatment and chemotherapy induce high levels of stress in patients with cancer, and apparently, these patients also experience depression upon every treatment cycle.

Moreover, some studies have demonstrated that hematopoietic stem cell transplantation (HSCT) recipients experience anxiety and depression at discharge.

Cancer rehabilitation has been improving since 2010 in Japan for QOL of cancer patients in their lives. And, there are some reports about practice of the patients with hematopoietic stem cell transplantation and OT.

**Aims:** mThis study was to clarify the relationship between QOL and depression among patients with hematopoietic stem cell transplantation.

**Method:** In this study, 38 subjects (men, 11; women, 27; average age, 44 years) who received HSCT and Occupational Therapy during hospitalisation from 2005 through 2011 at Shinshu University Hospital were enrolled. All patients provided consent to be examined before HSCT and upon discharge.

We used The Hospital Anxiety and Depression Scale (HADS) to measure anxiety and depression and MOS Short Form-36 Health Survey Ver.2 (SF-36) to measure QOL before HSCT and upon discharge.

HADS and sub-scale of SF36 were performed using Spearman's rank correlation coefficient. **Results:** Spearman's rank correlation coefficient revealed a significant correlation between HADS and GH ( $rs=-0.70$ ;  $p < 0.001$ ), VT ( $rs=-0.72$ ;  $p < 0.001$ ) before HSCT. And it showed a significant correlation between HADS and VT ( $rs=-0.70$ ;  $p < 0.001$ ). MH ( $rs=-0.70$ ;  $p < 0.001$ ) at discharge.

**Conclusion:** Before HSCT and at discharge there was a significant relationship between HADS and GH, VT. VT is said to be one of the evaluation indexes of cancer related fatigue. As a result, we found that cancer related fatigue was high in the depression state of recipients of hematopoietic stem cells.

Abstract number: P2-100  
Abstract type: Poster

### Implementation of a Patient Reported Outcome Measure (PROM) in a Brazilian Palliative Care Hospital Service

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**Background:** Evidence suggests that implementing PROMs in palliative care clinical practice is beneficial.

**Aim:** To describe the implementation of the Palliative care Outcome Scale (POS) in a specialist palliative service.

**Methods:** Longitudinal study. Tool selection criteria: developed for palliative patients, valid, feasible and freely available. The POS was chosen. Processes for POS use were defined. The pilot lasted 6 months. We used Wilcoxon signed-rank test to compare differences.

**Results:** We applied POS at admission, 3rd day and weekly to 401 patients with mean age of 75 years (±16). 53% were female and 44% were cancer patients. Pilot results (N=84) revealed inconsistent data collection and missing data (14%). Symptoms were sub optimally controlled by day 3, e.g. control of pain in POS rated as moderate at admission (Table 1). Processes changed: only cognitively intact patients filled POS (N=58 of 317). At admission, any team member participating in the patient/family conference could apply POS. After, the nurse managing the POS database would preferably do it. Doctors were encouraged to grasp the meaning of POS results for each patient, be more assertive in symptom control and more alert to treat patients displaying distressing symptoms. Control of pain rated as severe or moderate improved by day 3 (Table 1).

**Conclusion:** Roles and a daily routine to apply the POS were defined and symptom control improved. Gathering clinical evidence data on palliative care needs as perceived by the patients was paramount to inform the effectiveness of the care delivered.

Table 1. Patients scoring on POS item "Pain"

Pilot Phase (N=6/84)

Scores: 2 to 0 (n=3); 2 to 3 (n=1); no change (n=2) (p>0.131\*)

Study Phase (N=10/58)

Scores: 4 to 1 (n=1); 3 to 0 (n=2); 3 to 1 (n=1); 3 to 2 (n=2); 2 to 0 (n=2); 2 to 1 (n=1); no change (n=1) (p=0.005\*)

\*Wilcoxon signed-rank test

Abstract number: P2-101  
Abstract type: Poster

### Food and Oral Care at End of Life

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At hospice, many factors affect the quality of patient's meal experiences, including proper eating position, swallowing problems, food's consistency as well as oral and dental status. For patients with dysfunctions in the head, mouth and throat it is important to ease participation in what is possible and meaningful.

There is reason to believe that an increased focus on the importance of food and introduction of helpful ways to aid eating can improve patients' general condition and joy of the meals.

Adequate knowledge, competence and attention of nurses are needed to provide an appropriate compensatory support. Patients themselves are not necessarily aware of the extent to which a loss of function may be corrected.

In 2011 the Project Meal Support was completed and implemented at a Danish hospice. The purpose of this project was to describe the professional skills required to eliminate or reduce the barriers, thereby preventing that the patients give up eating.

The project provides recommendations for specific ways to remedy dysfunctions, dysphagia and problems in the mouth. Such approaches improves quality of life for these seriously ill people through the enjoying of a meal and the socialising this may be associated with.

We present a poster that will draw attention to patients' oral status and present a special screening tool called ROAG-pal. It is used upon admission to hospice to identify patients' oral care problems, so that the patients incipient and manifest problems in the mouth can be addressed immediately. Through appropriate nursing, the patient will achieve well-being in the mouth and can look forward to enjoying a meal.

Our poster will show what ROAG-pal is and how it is used as a screening tool, and the poster will point out some documented benefits.

Abstract number: P2-102  
Abstract type: Poster

### Predictors of Survival: A Study by a UK Hospital Palliative Care Team

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**Background:** Predicting the survival of terminally ill patients accurately is important as it facilitates clinical decision making and may avoid patients choosing invasive, active treatments and thereby a hospital death. Accurate prognostication is also desired by patients to reduce psychological burden.

**Aim:** To determine the survival of patients referred to a UK hospital palliative care team and to identify prognostic factors.

**Methods:** Consecutive patients referred to the hospital palliative care team were assessed and discussed at a weekly multi-disciplinary meeting. Demographic data, diagnostic information, Karnofsky performance score (KPS), clinical predication of survival (CPS) and length of time between admission to hospital and clinical assessment were recorded and later compared with actual survival.

**Results:** 371 participants were studied. The median age of the patients was 76 years, (IQR: 67–83 years); 52% (n=192) were male. The most frequent diagnoses were lung cancer (22%, n=81), upper gastrointestinal cancer (18%, n=64) and genitourinary cancer (13%, n=47). CPS was available for 242 (65%) of the patients. The median survival was 19 days, (IQR: 5–63 days). The median duration between admission and palliative care assessment was 10 days (IQR: 6–17days). In a multivariable logistic regression, survival 14 days after being assessed by the palliative care team was most significantly associated with the KPS (p<0.001) and CPS (p=0.0017). For a 10 point increase on the KPS, the adjusted odds of survival was 1.73 (CI: 1.35 to 2.21).

**Conclusions:** In patients referred to a UK hospital palliative care team, the KPS and CPS were the most useful predictors of survival at 14 days, when taking into account age, gender, diagnosis and duration between admission and palliative care assessment. Patients who scored 10 points higher on the KPS were 1.7 times more likely to be alive at 14 days compared to those with the lower score.

Abstract number: P2-103  
Abstract type: Poster

### Outcome Measurement in Palliative Care: An Updated Systematic Review of the Use of Two Popular Measures in Clinical Care and Research

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**Background:** The Palliative Care Outcome Scale (POS) and the Support Team Assessment Schedule (STAS) are outcome measures used to assess patient concerns and quality of palliative care. In 2011, Bausewein et al. published a review of the use of these measures, demonstrating widespread use in a variety of settings and translation into a range of languages.

**Aims:** The current work sought to update the results of the previous review to appraise whether and how the use of POS and STAS has changed over time.

**Methods:** The review applied the same search strategy used by Bausewein et al. and identified studies published from February 2010 to June 2014. Studies were categorised by main objective and reason for using POS/STAS. Further data on study design, location, population and results were extracted.

**Results:** Forty-three new publications met the inclusion criteria (35 for POS and 8 for STAS). These showed that use of POS and STAS has increased, particularly across Europe and Africa, including publication of 12 additional translations of POS in various African dialects. Publications reported use in 27 different countries. In most new publications, POS or STAS were used to assess patient concerns or measure quality of care (n=35, 81%). This indicates a shift in the way these measures are used, away from validation and reliability studies, and towards use as clinical or research tools. The review also found an increase in the use of POS and STAS with non-cancer patient groups.

**Conclusion:** POS and STAS have increasingly wide uses in clinical practice and research. The shift in the focus of publications may indicate that these tools have now been widely accepted as valid and reliable measures. There is advantage in having a brief, valid and reliable tool used across settings, languages and countries, not only to ensure palliative care concerns are addressed and outcomes of care are measured, but also to enable cross-country comparisons.

**Reference:** Bausewein C et al. *Pal Med*. 2011;25(4):304–13

**Abstract number:** P2-104  
**Abstract type:** Poster

## International Advances in Outcome Measurement in Palliative Care: One Step Closer to Cross-national Comparisons of Routinely Collected Outcome Data in Palliative Care

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**Background:** The Palliative Care Outcomes Collaboration (PCOC), Australia, and the Outcome Assessment and Complexity Collaborative (OACC), UK, support the routine use of outcome measures in palliative care. PCOC is a well-established programme; OACC commenced in 2014 and has built on PCOC's work. Both initiatives follow a sophisticated implementation approach, promoting routine clinical assessment tools that can be used to measure and benchmark patient outcomes.

**Design and aim:** The suites of measures used by PCOC and OACC were selected after consideration and consultation among experts in palliative care and research. We compare the two suites and assessment points in order to enable cross-national analysis.

**Results:**

Key Domain	PCOC Measure	OACC Measure
Stage of illness	Palliative Care Phase	Palliative Care Phase
Physical (Performance)	Australia-modified Karnofsky Performance Status (AKPS)	AKPS
Physical (Activity)	Resource Utilisation Groups – Activities of Daily Living (RUG-ADL)	10-item Barthel Index
Physical (Symptoms)	Palliative Care Problem Severity Score (PCPSS)	Integrated Palliative care Outcome Scale (IPOS)
"	Symptom Assessment Scale (SAS)	-
Psychological	PCPSS	IPOS
Spiritual	PCPSS	IPOS
Family/carer	PCPSS	IPOS
"	-	6-item Zarit Burden Interview

[Comparison of measures]

Both suites include tools to assess key domains in palliative care and both initiatives use a patient-reported outcome measure to examine symptoms and concerns (SAS and IPOS). However, individual measures for assessment of activities of daily living and symptom severity differ. Furthermore, only OACC includes a carer-reported tool to examine caregiver burden. Time points for measurement also differ. PCOC requires regular, ongoing assessment, while OACC recommends assessment on at least two occasions.

**Conclusion:** PCOC and OACC share a common goal and similar domains, however some individual measures differ. Nevertheless, availability of national outcomes data brings us one step closer to cross-national comparisons of routinely collected outcome data in palliative care.

**Abstract number:** P2-105  
**Abstract type:** Poster

## Ergonomic Self-assessment Tool – ESAT

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The aim of this project is to provide professionals working in Palliative Care (PC) – doctors, nurses, physiotherapists, etc. – with a practical means of assessing the quality of their work/treatment, in order to contribute positively to the achievement of the entire team. Therefore a tool for the professional that enables him/her to impact qualitatively on the overall work of the team. Project: to create a simple and effective reference tool designed to assess the quality of treatments by professionals in PC, in any setting. First phase, June/September 2014. Participation of professionals working in PC through individual interviews and team brainstorming (which assessment criteria can determine whether treatments are correct or not, well done or not, efficient or not, based on evidence or not) Processing of responses and identification of essential criteria. Second phase, October/November 2014. Design and preparation of a tool for using the self-assessment chart. The chosen tool is an extremely rapid and easy-to-use application for smartphones and tablets that will be launched and available from December 2014. Third phase, from January 2014. Experimentation of the ESAT chart through the involvement of professionals who have already taken part in the study phase and other work groups, with particular regard to physiotherapists. Seven assessment criteria have been identified (table), each with a corresponding value of 0–5; (-Expected effectiveness of treatment -Actual effectiveness of treatment -Based on evidence, based on shared results – Record of treatment - Communication / relationship with patient -Feedback (from patient and carer) – Appropriateness of treatment). All resulting data will be stored by the App and may be elaborated in Excel. Providing individual professionals with a tool that makes the quality of their work clearer, indicating aspects that can be improved, seems to be possible with this simple, easy-to-use tool. Study's source of funding: self-funded.

**Abstract number:** P2-106  
**Abstract type:** Poster

## Assessing Pain Severity – Which Scale Do Patients Prefer, and when Do they Need Treatment?

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**Background:** Pain assessment is the foundation of pain management and the patient's self report remains the gold standard of assessing pain. Use of standardised scales to measure pain severity is a recommended practice. Several studies have assessed optimal cutpoints for grouping pain severity, but there is still controversy in what constitutes mild, moderate, or severe pain.

**Aims:** To assess patients' preferences, at what point patients feel they need pain treatment, and the correlation between three pain severity scales commonly used in clinical practice: vertical and horizontal numeric scales, and verbal descriptive scale.

**Methods:** This is a prospective, descriptive study. Data will be collected from 70 patients 75 years and older, 70 patients on first day post-operatively, and 70 patients with chronic pain (N=210). The scales are presented in random order and patients fill out a questionnaire where they mark the pain severity and where on the scale treatment is needed. Afterwards, patients fill out another questionnaire querying which scale was preferred, pain interference, and demographic variables. Descriptive statistics will be used to portray pain severity, but correlation and ANOVA will be used to assess the relationship between the scales, and the difference between the patient groups.

**Results:** Data are being collected and will finish in January 2015. Results will be presented on which scale the patients preferred, how well the scales correlated, and where on the scales patients felt they needed treatment. The difference between the three groups will be portrayed, as will the relationship between interference with function and patients' evaluation on where they needed treatment, be explored.

**Conclusion:** The results will portray patients' preferences and can be used to guide treatment, and in training health-care professionals in pain management. The results will aid in providing optimal pain management and therefore improve the quality of care.

**Abstract number:** P2-107  
**Abstract type:** Poster

## Current Nursing Practice: Assessment of Anxiety in Advanced Cancer Patients. A Mixed Methods Study

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**Background:** Without structured assessment anxiety is one of the most overlooked symptoms in advanced cancer patients. Systematic assessment of anxiety is not imbedded in daily care. Anxiety management often depends on the clinical impressions of the bedside nurse. To improve structural assessment of anxiety, insight into the current practice and reasons for nurses to apply measurement instruments is needed.

**Aim:** To get insight into the application of instruments in order to improve structural assessment of anxiety.

**Methods:** An explanatory mixed method design. Retrospective data were collected from nursing files of advanced cancer patients admitted between Oct. 2012 – Feb. 2013 in an university hospital, general hospital and a high care hospice. In addition, semi-structured interviews were carried out.

**Results:** In total, 155 nursing files were analysed and 12 nurses were interviewed. Four different instruments were used to identify, screen or analyse anxiety. The frequency of used instruments and the frequency of reported anxiety by nurses in daily nursing files, differed significantly between settings. The main reasons to use instruments were improvement of communication with patients and other professionals. Lack of knowledge was the fundamental cause for neglecting suitable instruments, other factors were poorly imbedded multidisciplinary standards and patient- and environmental factors.

**Conclusion / Discussion:** A reason for increased frequency of anxiety mentioned in nursing files could be explained by the use of instruments. Although most nurses were convinced of the added value of instruments, they do not apply instruments because of patient and environmental factors but mainly due to a lack of knowledge on the application of these instruments. A training program for nurses, focusing on knowledge and competencies on the use of instruments in daily practice could be a first step to ameliorate anxiety management in practice.



## Audit and quality improvement

Abstract number: P2-108

Abstract type: Poster

### Integrating Palliative Care in a National Cancerplan

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**Goal of the work:** In Sweden, palliative care for cancer patients has been a separate entity, not always included in the regular health care system. However, according to our new Swedish national Cancer Plan, palliative cancer care should be a self-evident part of the patients' trajectory from diagnosis to death. Therefore, a Cancer Plan in palliative care is now one of ten defined areas in the implementation plan.

Our regional goal is to improve palliative cancer care from the patient's perspective in the Stockholm county council (2 millions), with respect to patient-centered care, patient safety, short lead-times, evidence-based knowledge, effectiveness and efficacy.

**Approach taken:** A registered nurse and a physician with scientific competence are project managers. In order to get a broad influence, the managers have:

Established co-operation with project managers representing specific tumor groups (e.g. gastro-intestinal (G.I. cancer).

Planned for dissemination of evidence-based knowledge both in palliative care and acute hospital care.

Planned for a comprehensive palliative cancer network within the County Council.

#### Results:

Establishment of a multiprofessional Regional Palliative Council, with members from different areas (specialised palliative care, acute hospitals, primary care etc.). Also representatives for patient associations are included.

An education program for all parts involved in palliative care.

Establishment of a system that aims at identification of chains of care for G.I. cancer with focus on lead-time and the cancer trajectory.

A pilot project of palliative consult teams in acute hospitals.

A pilot project of expansion of advanced homecare for children and youth.

Mapping of resources for palliative cancer patients in the whole region.

**Lessons learned:** When palliative cancer care becomes a self-evident part of the regular health care system, the allocation of resources increases and the palliative care patients become visible.

Abstract number: P2-109

Abstract type: Poster

### Collaboration in Palliative Home Care between General Practitioners and Palliative Care Team: A Survey

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**Background:** The public service of Palliative Home Care involves the collaboration between General Practitioners (GPs), District Nurses and Palliative Care Team (physician, nurse, psychologist). GPs play a key role in the Home Care.

**Aims:** The aim of our survey is to explore the views of GPs about Palliative Home Care, the perceived quality of Palliative Care Team (PCT) service and to evaluate proposals for improving cooperation between GPs and specialists.

**Method:** All GPs in the district received an anonymous questionnaire to be filled in on-line. Questions focused on criteria for palliative care referral, critical issues, educational needs, the perceived quality of service and suggestions. The questionnaire include closed ended questions (multiple choices and Likert scale).

**Results:** Response rate was 50.5% (145/287).

The 89% of GPs consider particularly useful the collaboration with the PCT especially regard to the symptom control and the ability to manage the patient at home until death.

The main criteria for referral to PCT are the life expectancy (90%) and the presence of symptoms (87%). The critical issues are the management of emergency (47%) and the difficulty of caregivers in administering medications (34%). Only 5 GPs reported issues in opiate use. GPs propose the establishment of a nursing team specifically dedicated and trained in palliative care (93%), the prompt availability of drugs at home (97%) and the opportunity to be trained on clinical and legal aspects of palliative care.

**Conclusion:** GPs consider that collaboration with specialists is essential in the management of terminally ill patients at home and expressed the need for more education in palliative care. They also suggest the enhancement of the nursing team with dedicated staff. The study had no external funding source.

Abstract number: P2-110

Abstract type: Poster

### "More Care, Less Pathway"- Is this Happening Post LCP?

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**Background:** The Liverpool Care Pathway for the Dying Patient (LCP) was devised to guide healthcare providers in ensuring uniformly good care to those at the end of life. Recently, it has come under scrutiny. An independent review in July 2013 prompted the LCP to be phased out. A holistic interim guidance was created to aid the provision of high quality care during the transition to a more individualised end of life care plan.

**Aims:** To establish the current quality of end of life care in the hospital setting compared to published interim guidance.

**Methods:** A retrospective case note review was undertaken. In total, 48 deceased patients' records from two city hospitals were analysed over one month. An 18 point template was devised based on the key principles of the interim guidance and used to review each set of case notes.

**Results:** Greater than 70% compliance was shown in only 4/18 areas audited. All notes contained documentation of the outcome of daily ward rounds and 89% of notes contained documented evidence that the patient's deterioration was discussed with family or significant others. The remaining 14/18 areas showed < 70% compliance. Notably, 0% of patient notes had documented that nutrition had been discussed and only 25% had documented a discussion regarding hydration. Compliance was significantly higher in 12/18 areas audited in cases referred to the hospital specialist palliative care team (HSPCT).

**Discussion:** Results demonstrate substandard compliance with the current interim guidance. Adherence to interim guidance was much improved by involvement of the HSPCT. Results may be explained by poor awareness of current interim guidance and/or the absence of paperwork to guide patient care.

**Conclusion:** Intervention in response to issues highlighted is essential to provide appropriate hospital palliative care. This may be facilitated by education of healthcare providers, a structured document to guide care and timely referral to the HSPCT. No funding was received for this work.

Abstract number: P2-111

Abstract type: Poster

### Launching a Bereavement Survey to Improve Hospital End of Life Care

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**Background:** How does a large hospital Trust with over 2500 deaths per year assess the quality of the end of life care provided to patients and families? The annual UK National Bereavement Survey (VOICES) provides locality data but is not refined to produce hospital specific data. To use feedback to improve the quality of end of life care in our two hospitals, a hospital-specific questionnaire was needed.

**Aim:** To design and implement a questionnaire to capture feedback from bereaved relatives on hospital end of life care.

**Method:** A questionnaire was designed with hospital specific questions and initially piloted on a single ward. After review and questionnaire amendments the project was extended in September 2013 to cover all adult deaths within the organisation. Amendments to the questionnaire addressed the main issues raised by the publication of the findings of the UK Government's Independent review into the Liverpool Care Pathway. The questionnaire is sent to relatives 6 weeks after the patient's death with a sensitively worded covering letter. The form has 25 'tick box' questions and a free text section, and telephone support is offered to relatives who want further discussion as a result of the contact.

**Results:** 1294 questionnaires were sent out in the first year, 436 have been returned; a response rate of 34%. The Trust Nursing directorate, Palliative Care Team and Clinical Governance department work in partnership to collect, analyse and utilise the data for quality improvement. Results inform education programs and help target service improvement.

**Conclusion:** The survey has given a voice to those who witness first hand the care provided to patients dying in our hospital Trust. Rich quantitative and qualitative data is collected and fed back directly to frontline staff to improve end of life care.

Abstract number: P2-112

Abstract type: Poster

### An Audit of the Change in Prescribing Errors and Dispensing Times Relating to Subcutaneous End of Life Care (EOLC) Medications for Palliative Patients Who Are Being Discharge from an Acute Hospital, Following the Introduction of a Dispensing Proforma across the Whole Hospital Trust

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Discharging palliative patients from hospital may require clinicians to prescribe medications to take out (TTOs) which can be given subcutaneously. Such medications may be needed on discharge for ongoing symptom control (e.g. in a syringe driver) or in anticipation of common symptoms (e.g. pain, secretions and agitation) that may develop as the patient deteriorates. Several such medications are controlled drugs which impose strict requirements on prescribing that must be met before a drug can be dispensed. Junior doctors, who most frequently prescribe TTOs, often appear not to remember or understand these requirements. The consequent prescribing errors can potentially delay the discharge from hospital of palliative patients.

A baseline 2 week survey within our hospital pharmacy department showed a high level (89%) of TTO prescribing errors for subcutaneous palliative medications (9 charts), especially for controlled drugs. The most common errors related to drug dose and strength, not writing total quantity required in words and figures, and signature omission. Average time taken for such TTOs to pass through pharmacy was 1 hour 25 minutes.

A multidisciplinary collaboration (between a palliative medicine consultant, hospital pharmacist and foundation doctor) led to development of a dedicated dispensing chart for the common subcutaneous medications used in palliative patients. The dispensing chart prompted good prescribing practice and aimed to reduce prescribing errors and dispensing times.

The dispensing chart was piloted over 2 weeks and errors and delays associated with the TTOs recorded (9 charts). The proportion of charts with prescribing errors reduced to 11% and the time taken by pharmacy to dispense was reduced to 1 hour. Following the pilot, the dispensing chart was ratified and rolled out across the hospitals Trust. This paper presents the result of the full implementation audit and discusses this within the context of implementing change and education.



**Abstract number:** P2-113

**Abstract type:** Poster

### Place of Death; What Are We Documenting, and What Are We Achieving?

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**Background:** When a patient has a requirement for Palliative care identified, a needs assessment should be undertaken and the patient's wishes explored. This audit examined the recording of preferred place of death (PPOD) in hospice patient documentation and numbers who achieved PPOD.

#### Aims and objectives:

(1) To review a sample of Inpatient Unit (IPU), Day Hospice, Community and Outpatient users at the Hospice and establish the percentage with documented PPOD.

(2) To review place of death and whether PPOD was/was not discussed/achieved and any documented reasons for this.

**Methodology:** A representative, retrospective electronic case-note and Clinical Portal review of 48 Hospice patients who died between January and March 2014.

**Results:** 81.25% (39) of the 48 patients had PPOD recorded. 4.17% (2) patients had no PPOD recorded but with reasons for this documented. 14.58% (7) had no documented PPOD without explanatory reasons recorded. 82.05% (32) of the 39 patients with a recorded PPOD achieved their PPOD, the remaining 17.95% (7) patients all had clear reasons for failing to achieve their PPOD.

Percentages achieved within each of the Hospice services:

- 66.67% of Outpatients had PPOD documented and 50% of these achieved PPOD.
- 88.89% of Day Hospice users had PPOD documented and 75% of these achieved PPOD.
- 73.33% of IPU users had PPOD documented and 100% achieved PPOD.
- 83.33% of Community services users had documented PPOD and 80% achieved PPOD.

**Conclusion:** Within the Hospice we have been successful in several areas with regards recording and achieving PPOD, while other areas still require further examination. This poster will expand further on the above data and discuss barriers to achieving PPOD. Feedback to the different hospice service groups on current levels of recording and achievement will be undertaken to promote and encourage improvements and maintenance of standards.

**Funding:** No funding was required for this audit to be completed

**Abstract number:** P2-114

**Abstract type:** Poster

### A Pain Audit at Regional Cancer Centre of India: Assessing Psychosocial Distress in Cancer Pain is the Need of the Hour

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**Aim:** Recent work in palliative care has recognised that pain is a complex social, psychological, spiritual and psychological experience. In order to assess if each of these components is equally well addressed in clinical practice, we undertook a retrospective audit of psychosocial assessment procedures at the pain clinic at IRCH-AIIMS, New Delhi.

**Methods:** 686 pain assessment forms collected over 2011 were examined and analysed through SPSS.

#### Results:

- 1) While physical aspects of pain are recorded at almost 100% levels in the pain forms, psychosocial components of patient distress are found to be less adequately recorded.
- 2) The layout of the assessment is slanted towards functional factors (such interference with daily activities and mobility), while non-functional symptoms are being recorded at relatively low levels (anxiety – 1.2%, depression – 4.4%). Prior studies in the same clinic as well as in the Indian psycho-oncology literature has shown that non-functional distress (such as anxiety and depression) are usually found at much higher rates of incidence (33%–80%).
- 3) Analysis of the existing data revealed severe demographic vulnerabilities in our patient sample, an aspect that is recorded but not currently addressed as part of a psychosocial assessment.

**Conclusions:** In light of these findings we surveyed 14 existing pain assessment tools, and chose two for incorporation into our existing pain practice. These tools were the Distress Inventory for Cancer – 2 and the American Pain Society Patient Outcome Questionnaire. They were chosen for their balance between functional and non-functional symptoms, sensitivity to socioeconomic distress and ease of completion in the high volume public health scenario.

**Abstract number:** P2-115

**Abstract type:** Poster

### Time & Motion: Transferring NHS Productive Ward to a Hospice Setting

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**Background:** The NHS (National Health Service) Institute for Innovation & Improvement supported the NHS to transform healthcare for patients & the public, by rapidly developing & spreading new ways of working. The Strategic Clinical Network agreed to fund the cost of supporting participating Hospices through the programme.

**Aim:** We concentrated on two modules in Phase 1:- Well Organised Working Environment & Knowing How We Are Doing. The focus was on improving ward processes & environments, whilst exhibiting openness & transparency in reporting systems & governance issues. Staff equipped with knowledge & practical tools developed skills to identify areas for sustainable efficiency improvements in terms of care, effort & finance whilst improving experience of care for patients & staff.

**Method:** Action learning training days followed external training, attended by various staff disciplines from all participating hospices. Phase 1 examined staff time spent looking for equipment & stores during a routine working day & the length of time preparing for clinical procedures. It prompted examination & analysis of everyday tasks. A mapping process was

undertaken, we carried out & filmed activity walks, looking at both location of equipment & time taken to carry out tasks. Organisation of stock storage in all areas was closely examined, identifying surplus stock & implementing changes to ordering system.

**Outcome:** The key to the success of the programme was that improvements were driven by staff themselves. Staff felt empowered to ask difficult questions about their own practice & made positive changes to the way they worked, ultimately working more efficiently & effectively, reducing cost & re-investing time in patient care. Having support from Hospice leaders led to an environment where changes were made but ultimately sustained. Phase 2 is now underway & includes the Ward Handover & Meals modules.

**Abstract number:** P2-116

**Abstract type:** Poster

### Introduction of a New Prescription Chart to a Specialist Palliative Care Unit

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**Background:** A redesigned inpatient prescription chart was introduced across 3 wards in a specialist palliative care unit in September 2013.

#### Aim:

To assess whether the new prescription chart is fit for purpose.

To survey opinions of those using the new chart.

**Methods:** Prescription charts of all inpatients (n=47) on a given day along with charts of 14 patients who had died were reviewed across 3 wards. Data collected included completion of each section of the chart, number of medications prescribed, use of specialist sections and documentation of administration of medications.

A user survey was carried out to assess opinions on the new prescription chart (n=19).

**Results:** 66 prescription charts were reviewed for 61 patients. Lack of space for regular medications caused the requirement for a second chart in 80% of cases. All patients who required two charts were inpatients for >1 month. While patient details were completed 100% of the time, allergies were documented only 85% of the time. The new signature bank was fully completed by nursing staff in 15%, medical staff in 17% & pharmacists in 100%. 64% were prescribed a regular opioid, 42% an antibiotic & 30% were prescribed fluids. The "PRN opioid" section was the most commonly rewritten.

Compared to the previous prescription chart, staff felt it was "much better" (58%) or "somewhat better" (26%). The main advantages were improved clarity of prescription & reduction in multiple charts in use at once. 79% felt a separate opioid section was safer while 42% felt an antibiotic section was safer.

**Discussion:** The redesigned prescription chart includes features that improve safety and clarity of prescribing and administration of medication. Most staff agree that the new design is an improvement but further modifications will be informed by this audit.

**Abstract number:** P2-117

**Abstract type:** Poster

### A Quality Improvement Journey in Palliative Care: Enabling Reliable Person-centred Care through Information Reconciliation

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Recent research<sup>1</sup> identified that 29% of patients in hospitals are at risk of deterioration & dying. The need to improve anticipatory care planning (ACP) for such patients requires innovative & system wide approaches.

**Aim:** To ensure patients in pilot areas receive care aligned to their needs & wishes through integration across hospital & community.

**Methods:** The Institute of Healthcare Improvement Model for Improvement<sup>2</sup> is used to explore the current system, challenge assumptions & test changes regarding:

- Identification of patients at risk & reliable response
- Communication with patients & families regarding realistic goals, benefits/burdens of interventions, their wishes & concerns
- Integration of core elements of ACP within routine clinical processes
- Clear documentation of a multi-professional Goals of Care plan & sharing of information across care settings: information reconciliation

This iterative, participative approach has ensured clinician ownership. Measures used to evidence the reliability of processes & impact on patient outcomes will be reported. Data capture includes audit of clinical documentation, observations of Professional clinical practice and semi-structured interviews with patients, carers and staff.

**Findings:** Findings from pilot areas challenge current literature by indicating that ACP is appropriate for over 75% of patients in pilot areas. This presentation will include the impact of interventions on care processes & outcomes including acceptability of ACP approaches.

#### Additional output:

Exploration of a core skill set for staff regarding best practice

Glossary of terminology has been defined to enable a consistent approach.

Collaboration to expedite progress.

Testing of quality improvement approaches in palliative care.

1. Clark et al (2014) Imminence of Death Among Hospital In-Patients. Pall Med 28(6)474–9

2. www.ihl.org/resources/Pages/HowtoImprove/ScienceofImprovementHowtoImprove.aspx

**Abstract number:** P2-118  
**Abstract type:** Poster

## Acupuncture for Hot Sweats: Kindling the Flame

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Acupuncture is increasingly becoming recognised as a clinically useful tool in the management of difficult or distressing vasomotor symptoms. Currently limited evidence suggests the need for more rigorous research to define its role in oncology and palliative settings.

This was a retrospective case-note review with detailed case studies to investigate the effectiveness of treatment with acupuncture for the relief of hot sweats. The sample consisted of 46 patients who had been treated for sweats in a hospice setting since records began in 2006. Collated data included patient details and diagnoses, number of treatments, quantitative scores for symptom intensity and frequency, the type of acupuncture (needle or electro), plus qualitative comments. In addition, the data lent itself to detailed case studies profiling a smaller subset of patients through their treatment process. 23 (50%) of the 46 patients showed symptomatic improvement over the course of their treatment, with a further 5 showing a variable response. 6 patients did not experience any improvement of their symptoms, and the data was insufficient in the remaining 12 cases. Qualitative remarks included comments such as: 'pillow saturated', 'soaked', 'burning' before treatment, to 'now manageable', 'no need to wash sheets', 'virtually none' after treatment. Vasomotor symptoms can be debilitating and difficult to control. In this study, patients experienced a dramatic improvement in the frequency and intensity of their hot sweats over their treatment course. More rigorous recording and research would be needed to understand the procedure process, to include the duration and quality of treatment needed to bring about an improvement. Clearly though, the use of acupuncture in a palliative environment has enormous therapeutic benefit, which may be clinically relevant. The application of acupuncture for the management of other palliative symptoms, for example, pain and insomnia, should also be considered.

**Abstract number:** P2-119  
**Abstract type:** Poster

## Assessment of Therapeutic Adherence to Strong Opioids in a Sample of Advanced Cancer Patients Attended by Specific End-of-Life Support Teams. A Pilot Study

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**Background and aims:** Pain is a highly prevalent symptom among advanced cancer patients affecting severely their quality of life. Lack of adherence with the analgesic regimen can be a significant barrier to effective cancer pain management. The purpose of this pilot study is to determine the degree of adherence to the third step of analgesic drugs in a sample of advanced cancer patients cared for specific end-of-life teams.

**Methods (design, data collection, analysis):** We conducted an observational prospective study. We included consecutive patients attended both at home (home care team) or at the outpatient clinic (supportive palliative care team), between November 2013 and April 2014 being treated with strong opioids but with intensity of pain  $\geq 4$  measured on a visual analogical scale. We used the Morisky-Green-Levine test in order to determine the therapeutic adherence to the analgesic regime. We used univariate and multivariate tests to analyse variables.

**Results:** 89 patients were recruited (mean age  $70.3 \pm 14.143$ ). Men 64 (72%). Morphine Equivalent Daily Dose ( $76, 26 \text{ mg} \pm 74.73$ ). Non-adherence to treatment was detected in 42 patients (47, 2%). In the univariate analysis statistical differences were found between non-adherence and gender ( $p=0.047$ ), transdermal route of delivering the strong opioid ( $p=0.004$ ) and side effects in woman ( $p=0, 0024$ ). The multivariate analysis shows that the transdermal route is the single variable associate to non-adherence to the analgesic regime [ $p=0.017$ , IC 95% (0,077–0,774)]

**Conclusions:** In this pilot study non-adherence to analgesic regime is highly prevalent. The main reason for the non-adherence to the analgesic regime is being treated with transdermal strong opioids. The Morisky-Green-Levine test is an easy way to detect non-adherence behavior in advanced cancer patients. Due to the sample size it is mandatory to design a bigger study to confirm the data obtained.

**Abstract number:** P2-120  
**Abstract type:** Poster

## Does the AMBER Care Bundle Have a Role in a Specialist Cancer Hospital?

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**Background:** The AMBER care bundle is a hospital based tool designed to improve the quality of care for people where recovery is uncertain. The regional cancer centre serves a population of 2.3 million, with an average of 4500 inpatients a year. There was concern that many ill patients and their families would benefit from a more structured approach to communication about uncertainty of outcomes, ceilings of care and treatment decisions. It was felt to be an ideal setting to consider implementation of the AMBER care bundle.

**Aim:** The aims of the project were:

1. To assess the current level of care.
2. To implement the AMBER care bundle onto the inpatient unit.
3. Evaluate implementation of the AMBER care bundle.

**Method:** A retrospective review of case notes was conducted on 30 patients who had died under the care of the Centre. 15 had died on the inpatient unit and 15 had died within 100 days of discharge. Data collected included: demographics, suitability for AMBER care plan, existence of a medical plan and decisions around resuscitation. The documentation of discussions with patients/families, preferred place of care and the daily reviews were also analysed.

**Results:** The review showed that 15 patients who died on the inpatient unit would have

been suitable for the use of the AMBER care bundle. 86% had a medical plan, escalation decision and DNACPR conversation recorded; 73% had a documented conversation with the patient and/or relative about uncertain recovery. 46% had a documented discussion about preferred place of care. 20% showed evidence of the medical plan being discussed and agreed with nursing staff. 60% did not receive daily follow up.

**Conclusion:** Implementation of the AMBER care bundle will help focus on the areas of care that need improvement. Education and resource material will be essential in achieving and sustaining a change in practice.

**Abstract number:** P2-121  
**Abstract type:** Poster

## Aneurin Bevan Health Board End of Life Admissions Audit

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**Background:** Advance care planning is fundamental to providing high quality care to those approaching end of life. Anecdotally, unscheduled admissions and subsequent deaths in hospitals are increasing despite patients' preference to die at home. The aim of the audit was to explore whether palliative patients with an unscheduled admission had an advance care plan in place, and whether there were any missed opportunities to explore advanced care planning with these patients prior to death.

**Methods:** A 1 month retrospective cohort of patients who died within 48 hours of admission across Aneurin Bevan Health Board was identified. Those who died unexpectedly were excluded, and the remainder assessed using the clinically validated 'surprise' question ('Would you be surprised if this patient died within the next year?'). Patients were then classified as palliative if the answer was 'no'. Palliative patients' case notes were reviewed and data collected.

**Results:** Of 50 patients in the original cohort identified, 34 were unexpected deaths, with the other 16 deemed palliative (3 were discarded due to incomplete data). Of these 13 patients the mean age was 75.8 years with 69% being admitted out of hours. 77% had a performance status of 3 or 4. 100% of patients from nursing homes had a performance status of 4. 100% had at least 1 admission in the year prior to death (median = 3), but only 2 had advanced care plan in place.

**Discussion:** A proportion of patients nearing end of life are dying in hospital. Our audit has highlighted the absence of advanced care planning for the majority of these patients, and missed opportunities to explore advanced care planning during their multiple previous admissions. The emphasis on advanced care planning appears focused on the community setting, but a cultural change within secondary care may facilitate a wider appropriate use of advanced care planning.

**Abstract number:** P2-122  
**Abstract type:** Poster

## Visits to Hospital Emergency Patients Seen by the Support Team Palliative Care Merida Area

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**Aim:** To determine the patients in the Regional Palliative Care Program of Extremadura (PRCPEx) who visit hospital emergencies in the area of Merida.

**Design and method:** Observational, descriptive, retrospective study. A review of medical records of patients who were included in the PRCPEx was performed, and the following data were collected:

- Location of patient care, depending on the degree of stability: active / passive or unstable / stable.
- Number of visits to the emergencies service.
- Reason: Pain, other symptoms (dyspnea, asthenia, anorexia, dysphagia, and malaise), patient decision and family overload.

**Results:** A total of 156 patients were registered in the period from January 1 to June 30 of 2014, which 11 of them weren't included for not meeting criteria, so that the sample was at 146. 65 patients were included (45%) they generated 90 episodes (average 1.38, mode 1) 90 episodes were produced, 73% were active patients, 27% were passive and 68% needs hospitalisation.

The reasons why these events occurred were related with pain 32%, and other symptoms different than pain 68%.

In 13 (14%) episodes, were detected 2 or more reasons, being these the overload of the caregiver (46%) and with other symptoms than pain (64%)

**Conclusions:** We think that even we provide the last days assistance at home, there are a high percentage of patients who comes to the emergency department of the hospital to manage their symptoms and this could be done on an outpatient basis.

It is true that two-thirds parts of the episodes occurred in "active" patients, status that we consider as "complex patients"

We still planning to review our protocols, to inquire into the patient's wishes about where they want to be in case of complications and improve the information, health family education about uncontrolled symptomatic situations and professionals training.

**Abstract number:** P2-123  
**Abstract type:** Poster

## **Bridging the Gap between Practice and Research: An Analysis of the 'Bottom-up' Approach within an Outcome Measurement Implementation Project**

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**Background:** Implementing outcome measurements (OM) in a palliative care clinical environment has rarely been researched. Evidence recommends a 'bottom-up approach'; facilitating teams to maintain ownership throughout implementation. It is unclear, what such an approach means in practice. The Outcome Assessment and Complexity Collaborative (OACC) is implementing patient-level OM and researching the best ways to undertake this.

**Aim:** To develop the complex intervention of implementing OM, using Quality Improvement Facilitators (QIF) and a bottom-up approach with the clinical teams, and to determine the components of this approach.

**Methods:** Content analysis of observational field notes with review of emerging themes by clinical stakeholders and the implementation team in order to establish consensus regarding the key components of the approach.

**Results:** This project is running in 6 organisations delivering specialist palliative care. We determined that a 'bottom-up' approach should have the following characteristics: *Empathic attitude:* The QIF has to understand the clinical workload of each team in order to demonstrate credibility and approachability.

*Balancing project and clinical priorities:* Strict timelines mean each clinical team must balance time requirements to avoid jeopardising implementation.

*Emphasis on practical applications to aid clinical work and outcomes:* Tailored solutions for implementation were created to address clinician concerns. Including: time reduction in writing patient notes; practicing the completion of OM; and adding the new OM as routine documentation.

**Conclusion:** A 'bottom-up' approach that integrates innovative ideas from clinical teams is essential when implementing OM. Flexibility, responsiveness and receptiveness to clinical input is critical. Qualitative research is required to further develop the complex outcome implementation intervention in order to bridge the gap between research and practice.

**Funder:** Guys & St Thomas' Charity

**Abstract number:** P2-124  
**Abstract type:** Poster

## **Satisfaction of Patient's Family: Experience from a Newly Created Palliative Care (PC) Unit**

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**Objective:** This study was to evaluate the satisfaction and psychological status of the families of patients treated by the new palliative care mobile unit of the Bafoussam Regional Hospital (Cameroon).

**Methods:** A descriptive cross-sectional study was carried out on all the patients' carers received during the first year of activities of the unit. These patients' carers were contacted by phone by a person out of the patients' caregiver team. Data were collected using a standard questionnaire completed by the respondents.

**Results:** Of the 47 patients' carers followed up, 39 were able to respond to the invitation. The average age of respondents was  $39 \pm 12$  years. Sex ratio (M/F) was 0.56. Four (04) respondents were caring for a non cancer patient. Regarding patients' carers satisfaction, 95% of respondents were at least somewhat satisfied with their reception by the PC team. 84% (33/39) were satisfied with the information provided by the medical team on the health of their patients. 87% (34/39) were satisfied with the information given on the investigations requested and carried out. 72% (28/39) were satisfied with the answers given by the doctor to their questions. 97% were satisfied with the relief of the physical pain. 56% (22/39) were satisfied with the psycho-social support. 74% (29/39) were satisfied with the respect of their privacy and dignity during their stay. 74% (29/39) felt prepared to accept the death of their patient. 95% (37/39) could advise a relative to be managed by a palliative care team if it was indicated.

**Conclusion:** This study shows a good satisfaction of the families of patients receiving palliative care, with a greater appreciation of the management of physical pain and a good preparation to accept the death of their loved ones. The weak point of the care was the psycho-social support, suggesting the need for a holistic approach to improve satisfaction.

**Abstract number:** P2-125  
**Abstract type:** Poster

## **Why Are Hospice Patients Transferred to Hospitals? An Audit of Patients Transferred to Hospital from a Specialist Palliative Care Unit**

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**Background:** On average a person in the UK has 3.5 hospital admissions during their last year of life. Increasingly, hospice patients are receiving 'active' treatments in addition to specialist palliative care meaning that transfer to hospital might be appropriate for treatments not available at the hospice. Weighing up the burdens and benefits of transfer to hospital can be difficult for patients and clinicians.

**Aims:** Retrospective audit of patient transfers from a Specialist Palliative Care Unit to hospitals over a 2 year period, August 2011 – August 2013.

**Methods:** Retrospective case note analysis and independent assessment by the investigators of appropriateness of transfer. Any differences of opinion were discussed.

Results were compared with the audit standard that 100% of transfers to the hospital were appropriate.

**Results:** 14 patients were transferred to hospital. The reasons for transfer were: acute medical problem (8), rehabilitation/discharge planning once patient no longer had specialist palliative care needs (5), planned procedure (1). Average length of admission to hospital was 13.6 days. 13 of these transfers were deemed to be appropriate by the authors.

**Discussion:** There are no national statistics regarding patients transferred to hospitals from hospices. The most common reasons here for transfer were need for intravenous antibiotics and rehabilitation and discharge planning once specialist palliative care needs had been met.

**Conclusion:** In general, hospital transfers were appropriate. Since the time period studied there has been a change in documentation of ceilings of care and increased ability to provide intravenous therapies at the hospice. A repeat audit is planned to examine the impact of these changes.

**Abstract number:** P2-126  
**Abstract type:** Poster

## **Round Table Discussions in Palliative Situation – Qualitative Interviews with Patients**

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**Background and aim:** Since the introduction of the concept of palliative care in a cantonal hospital in Switzerland in 2006, mainly quantitative data for evaluation of quality standards has been collected. Evaluation of experience of round table discussions (rtb) by patients is completely lacking. For this reason, qualitative interviews with patients have been conducted from August 2014.

**Method:** Each patient where a rtb was held, has been screened. If the patient is eligible, he/she will be invited for a narrative interview within a maximum of 7 days after the rtb.

**Inclusion criteria are:** patient in palliative situation, older than 18 years, all divisions of hospital, all diagnoses, inpatient, is able to communicate and decide whether he/she wants to participate in the interview, understands and talks German. If the patient consents, he/she then is invited to freely talk about experiences during rtb. Guiding questions are framing the interview. Interviews are taped and transcribed and evaluated with qualitative content analysis. 20 interviews are aimed for.

**Results:** By the end of September 2014 out of 55 patients where a rtb has been held, 12 patients have been eligible. Out of this, 4 interviews (33% of eligible patients) have been conducted. Reasons for drop outs: no documentation about rtb was found at care unit, attending physician resp. nurse dissuades from asking for consent, discharged from hospital

**Discussion:** First results suggest that not all units in the hospital define a rtb similarly and physicians and nurses at care units have to be instructed that at least two professions have to participate in a rtb in palliative situation. Further important information to improve quality of care is expected from the interviews and the recruiting process.

**Abstract number:** P2-127  
**Abstract type:** Poster

## **Coverage of Cancer Patients by Hospice Services in a Medical Center**

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**Introduction:** Under Taiwanese national policies of promoting quality of cancer care, MacKay Memorial Hospital began to follow the coverage of cancer patients by hospice services. The definition of coverage is the dead cause by cancer who had received any types of hospice services in his/her last 6 months. The types of hospice care included admission in palliative care units, palliative consultant teams, and palliative care services at home. The survey is to understand the tendency of coverage.

**Method:** We collected the data from the medical record room from January 2009 to September 2014. The denominator of coverage is all dead with cancer diagnoses, and the numerator of a fraction is as the definition as previous statement.

**Result:** There were 6,148 cancer patients died during the period, and 3,515 accept hospice services (coverage: 57.17%). During the first three years, the tendency of coverage was significant increased. However, the coverage became fluctuated from 2012 to 2014.

Sometime the admission in palliative care units provided the highest part of coverage, but sometime the palliative consultant teams did.

**Conclusion:** Higher coverage of cancer patients by hospice service means higher quality of end-of-life care. Based on the survey, we have to inspect our hospice service system to improve our service quality of end-of-life care.



**Abstract number:** P2-128  
**Abstract type:** Poster

## Towards a Continuous Quality Cycle for Palliative Care Guidelines in the Netherlands

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**Aims:** Our organisation develops guidelines and quality criteria for oncological and palliative care in collaboration with scientific and professional associations, patient federations and other (inter)national partners.

In 2013 we investigated the acquaintance and satisfaction with palliative care guidelines. Of the 1.443 respondents 93% knew the guidelines and used them for decision making and informing patients. On the following topics room for improvement was identified:

1. Relation with scientific and professional associations
2. Methodology of guideline development
3. Integration of palliative care in oncological guidelines.

### Methods:

1. A multidisciplinary platform (PAZORI) was established, consisting of mandated members of scientific and professional associations.
2. A continuous quality cycle for palliative care guidelines has been introduced (phases: topic selection, preparation, development concept guideline, consultation, authorisation, implementation, evaluation and revision).
3. A guideline module palliative care is being developed.

### Results:

1. PAZORI gives advice about development, implementation and evaluation of palliative care guidelines. PAZORI identifies problem areas, prioritises topics, contributes to improvement of guideline methodology and to the integration of palliative care in other guidelines.
2. Two guidelines ('anorexia and weight loss' and 'nausea and vomiting') have been developed according to the continuous quality cycle.
3. The module palliative care is in development, to be integrated in all oncological guidelines.

**Conclusions:** Guidelines for palliative care have been improved by increasing the involvement and commitment of professionals through the creation of a multidisciplinary platform and by introducing a continuous quality cycle. Furthermore, implementation is being accomplished by integrating a module of palliative care in oncological guidelines in order to give palliative care the attention it needs in cancer patients.

**Abstract number:** P2-129  
**Abstract type:** Poster

## Malignant Bowel Obstruction: A Team Approach?

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**Background:** Malignant Bowel Obstruction is a multi-disciplinary (MD) clinical issue associated with long length of hospital stay and inconsistent clinical practice. To improve patient care and to enable transfer to more appropriate clinical settings, a coordinated and timely approach to the management of malignant bowel obstruction is needed.

**Aims:** The aims of this retrospective audit were to review the timeliness of the MD approach to managing patients in bowel obstruction with a gynaecological malignancy in a tertiary referral oncology centre.

**Methods:** The electronic medical records of all in-patients who had a diagnosis of bowel obstruction recorded on discharge summary were reviewed over a six month period. Palliative Care patient lists for that period were also reviewed. Data was collected on date of diagnosis of malignant bowel obstruction, date of surgical, oncological, palliative care and dietician review. The use of nasogastric tubes, and steroids (dose and route) was gathered. Length of stay and time to death were also reviewed.

**Results:** 18 patients (12 Ovarian, 4 uterine and 2 primary peritoneal cancer) were included. 39% patients had surgical review within 48 hours. None of the patients had surgical intervention. 94% patients had senior oncological review within 24 hours. 56% patients had specialist palliative care review within 24 hours. 78% patients were given steroids at varying dosing schedules and routes. 5% patients had dietician review within 48 hours and 50% patients were offered NG tube at diagnosis. The average length of stay was 19 days and the average time to death from diagnosis of malignant bowel obstruction was 79 days.

**Conclusion:** The MD review did not occur in a proactive or timely manner. To combat this, MD guidelines were agreed and disseminated widely with education amongst the palliative care, dietician, surgical, and oncology teams and there is now a collaborative approach. A prospective audit is ongoing to evaluate the intervention.

**Abstract number:** P2-130  
**Abstract type:** Poster

## The Mental Capacity Act 2005 (MCA) and Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)

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**Background:** Once a decision has been made by a clinician not to attempt cardiopulmonary resuscitation (DNACPR), the person should be informed unless it would cause the person physical or psychological harm (Tracey v Cambridge, University Hospital NHS Foundation Trust). Where the person is deemed to not have capacity, then the MCA 2005 should always be followed. This places the person who lacks capacity at the heart of the decision-making, ensuring their choices are respected and that decisions made for them are in their best interests.

**Aims:** To develop a DNACPR form and policy that can be used by clinicians, which includes the taking into account of the MCA 2005. The forms will have clear guidelines on how to assess for capacity and what to consider when making a best interest decision.

**Method:** An audit was undertaken to establish whether clinicians consider a person's mental capacity when making decisions about CPR. A professional group was set up to establish a policy and develop forms to be used for all persons where a DNACPR decision is

made. Research was conducted into what information and forms other Trusts use for patients without capacity where resuscitation is inappropriate.

**Results:** The audit showed that clinicians have limited knowledge about the Mental Capacity Act 2005.

Mental Capacity Act assessments were not being carried out in relation to the decision around DNACPR.

The best interest checklist was not being followed in relation to making a decision on DNACPR.

Documentation was poor in relation to the patient's mental capacity and the decision made regarding DNACPR.

**Recommendations:** To deliver a training programme for clinicians on the MCA 2005, and how it relates to DNACPR. To develop DNACPR forms which include the Mental Capacity assessment and best interest checklist.

**Abstract number:** P2-131  
**Abstract type:** Poster

## Audit in Palliative Care: Appropriateness of Intravenous Devices in Hospice

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**Background and aims:** Are the intravenous devices in Palliative Care (PC) being used excessively? And what are the most suitable? Data from literature is discordant. Till 2012 in Hospice, the short Peripheral Intravenous Catheter (PVC), was used for infusion therapy (IT), the alternative was a short-term Central Venous Catheter (CVC), but this required the transfer of the patient by ambulance. The launch of a PICC-team inside the Hospital started a reflection on the use of these devices of media-long term in hospice.

**Methods:** Clinical audit on the appropriateness of the intravenous devices used in Hospice.

### Results:

**Measure practice against standards:** A prospective surveillance was conducted in 2011 collecting data from 53/81 pts. admitted undergoing therapy infusion. The number of venipunctures, days of exposure to PVC, days of hospitalisation and life expectancy, were defined as indicators. In particular 35/53 pts. were analysed.

**Compare performance with criteria and standards:** The team concluded that 6/35 pts. would have needed an intravenous device of media permanence.

**Implement change in practice:** A pathway of positioning PICC /Midline catheters at the bedside of the patients in hospice was created.

**Re-audit to ensure change has been effective:** A new prospective surveillance was conducted in 2014 collecting data from 88 pts. admitted in Hospice.

19/88 pts. carried a central venous access when admitted, 13/19 had a PICC, 4/19 a Midline, 2/19 a CVC.

62/88 pts. needed IT. 17/62 pts. were analysed. 2/17 had a Midline positioned after 8 days of hospitalisation and the survival after the positioning was respectively 6 and 11 days. The team is uncertain about the correct timing of the Midline positioning.

**Conclusion:** The team retains that the PICC/midline is an appropriate alternative to PVC. Clinical audit is confirmed as an effective tool to assess the quality of care. This has allowed us to identify critical areas leading to improvements in the clinical practice.

**Abstract number:** P2-132  
**Abstract type:** Poster

## Strategies for the Implementation of Quality Indicators across 4 Settings in 5 Countries

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**Introduction and aim:** The overall aim of the IMPACT study is to develop strategies for the implementation of quality indicators (QIs) to improve the organisation of palliative cancer and dementia care in Europe. For this purpose, a set of 23 QIs was pretested among 40 services across 5 European countries (D, ENG, IT, NL and NO). The services then chose up to 3 QIs with low performance for (better) implementation. The aim of this part of the study is to analyse the strategies used across countries and settings.

**Methods:** Implementation processes were accompanied by advising consultants and recorded on standardised documentation sheets covering aims, timelines, methods, barriers, facilitators etc. National results were compiled using a country report template, including relevant qualitative data (quotes from participants). All country reports were analysed and categorised inductively according to the PRECEDE-PROCEED model: predisposing factors (for a specific behaviour); enabling factors (for the change); reinforcing factors (for the implementation).<sup>1,2</sup> The implementation strategies were analysed according to <sup>2</sup>.

**Results:** All chosen strategies across settings and countries were organisational interventions or professional-oriented. There were no patient-oriented strategies or financial measures. Knowledge, needs awareness and attitude were predisposing factors; networking, and resources were the most enabling factors. Organisational support decided about success of implementation.

**Conclusions:** Bottom-up strategies were important for motivation. Implementation of improvement needs time, staff and money. Qualitative data strongly suggest that some barriers cannot be overcome without support from political decision makers.

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2) Grol R, Wensing M. Selection of strategies. In: Grol R, Wensing M, Eccles M. Improving patient care. The implementation of change in clinical practice. Elsevier 2005, pp. 122-134



**Abstract number:** P2-133  
**Abstract type:** Poster

## Reaching out to Work with Others: How a Hospice Is Using Bereaved Carers' Views to Improve End of Life Care in UK Residential and Nursing Care Homes

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**Background/aims:** Many frail elderly people are living and dying in care homes. This audit uses a validated tool, the Family Perception of Care (FPC) Questionnaire, to understand and learn from bereaved relatives' views about care provided to them and their relatives. Responses are used to help develop and improve end of life care provided by the care home staff, by extending and building upon their knowledge and confidence.

**Methods:** Views of bereaved relatives of deceased care home residents across five areas in England are sought, regarding care provision in the residents' last months of life. The audit is coordinated by a local Hospice with existing supportive links to the homes. Three months after a resident dies in the care home, the FPC questionnaire is sent out by care home staff to the bereaved relative, for anonymous return to the Hospice. The questionnaire consists of 28 questions, covering resident care, family support, communication and rooming, plus a space for comments, and a request to rank three questions considered most important for end of life care. Responses are analysed using SPSS and Excel. Results are shared anonymously with the 52 care homes six monthly. The Hospice then works with each individual home to develop action plans for improvement as part of the audit cycle.

**Results:** For the first six months, from 288 deaths there were 105 returned questionnaires (35%). Response rates varied by area (range 16% to 52%). Highest satisfaction rates were for staff friendliness, being treated with dignity, having privacy and overall satisfaction with care. Lower rates covered GP time and chaplaincy availability. Treating the resident with dignity was ranked as most important.

**Conclusion:** Most respondents were very satisfied with the care received. Items ranked lower were possibly out of the direct control of the homes. Finding a way to improve care in these items will involve working with the wider community. Funded by The Burdett Trust for Nursing

**Abstract number:** P2-134  
**Abstract type:** Poster

## Improving Palliative Care in Patients Admitted under Internal Medicine – A Pilot Study to Explore Characteristics of Inpatient Deaths & Determine Feasibility of Retrospective Case Record Study on Assessing Palliative Care Provision

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**Background:** In Singapore General Hospital (SGH), many patients admitted under the care of the Department of Internal Medicine (DIM) have a background of advanced chronic illnesses, recurrent hospitalisations for exacerbations as well as prolonged hospital length of stay due to functional decline and care issues. It is possible that some of these patients have palliative care needs, and may benefit from palliative care interventions to improve patient outcomes. In order to develop relevant palliative care interventions, it is necessary to explore palliative care needs in these patients.

**Aims:**

- 1) To determine the feasibility of a retrospective case record study in assessing quality of palliative care provision DIM patients
- 2) To explore the characteristics of inpatient deaths in DIM.

**Methodology:** A retrospective data collection was performed, using coded standardised collection form, on paper and electronic records of the first 50 patients who passed away during admission under DIM, from the period of 1st July 2014 – 31st August 2014. Data collected included demographics, diagnosis and other clinical information that may be relevant to palliative care needs or palliative care provision. Information collected was analysed using SPSS.

**Results:** Due to ongoing data collection, results will be available end of this year.

**Discussion:** The results will be useful in guiding further studies using retrospective case audits on identifying gaps in palliative care provision in DIM patients. Targeted interventions can then be developed to benefit such patients.

**Abstract number:** P2-135  
**Abstract type:** Poster

## How to Implement Quality Indicators Successfully in Palliative Care Services: Perceptions of Team Members about Facilitators of and Barriers to Implementation

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**Background:** There is an increasing demand for the use of quality indicators in palliative care in order to monitor the quality of care.

**Aim:** With previous research about implementation in this field lacking, we aimed to evaluate the barriers to and facilitators of implementation.

**Methods:** Three focus group interviews were organised with 21 caregivers from 18 different specialised palliative care services in Belgium. Four had already worked with the indicators during a pilot study. The focus group discussions were transcribed verbatim and analysed using the thematic framework approach.

**Results:** The caregivers anticipated that a positive attitude by the team towards quality improvement, the presence of a good leader and the possible link between quality

indicators and reimbursement might facilitate the implementation of quality indicators in specialised palliative care services. Other facilitators concerned the presence of a need to demonstrate quality of care, to perform improvement actions and to learn from other caregivers and services in the field. A negative attitude by caregivers towards quality measurement and a lack of skills, time and staff were mentioned as barriers to successful implementation.

**Conclusion:** Palliative caregivers anticipate a number of opportunities and problems when implementing quality indicators. These relate to the attitudes of the team regarding quality measurement, the attitudes, knowledge and skills of the individual caregivers within the team and the organisational context and the economic and political context. Training in the advantages of quality indicators and how to use them is indispensable, as are structural changes in the policy concerning palliative care, in order to progress towards systematic quality monitoring.

**Funding:** This study is realised with the support of 'Kom Op Tegen Kanker', a campaign of The Flemish League Against Cancer.

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**Abstract type:** Poster

## Management of Malignant Hypercalcaemia and Appropriateness to Treat – A Hospice-based Inpatient Audit

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**Context and aims:** Hypercalcaemia of malignancy affects 20–30% of cancer patients during their disease conferring significant morbidity. It frequently represents a poor prognostic sign with 50% of cancer patients with the condition dying within 30 days. Treatment comprises IV fluid resuscitation and IV Bisphosphonate therapy requiring the patient to be treated within a healthcare facility.

We audited current hospice management of malignant hypercalcaemia against local guidelines focusing on appropriateness to treat.

**Method:** A retrospective, single-centre audit was carried out. All patients with a recorded corrected calcium of  $\geq 2.6$  over a 1 year period were identified from the hospice database. Case notes were used to ascertain if the patients were treated, if hospice management was adherent to clinical guidelines, and the clinical outcomes.

**Results:** 68 patients with hypercalcaemia were identified. 20 patients were treated and aspects of management that deviated from the guideline were identified. 15 patients with corrected calcium levels of  $\geq 2.7$  were not treated. 80% of these had clear documentation specifying why treatment had been felt inappropriate. This reflected either the patient's rapidly deteriorating clinical condition or a desire for the patient to remain in a preferred place of care. The remaining patients had calcium levels of 2.6 and treatment was not offered.

Clinical outcomes were globally poor with only 30% of patients symptomatically improving following treatment. Average time to death following treatment was 25 days.

**Conclusion:** Appropriateness to treat malignant hypercalcaemia should be considered carefully due to the condition's poor prognosis. Decisions to treat are likely to be influenced by the patient's current and preferred place of care.

**Abstract number:** P2-137  
**Abstract type:** Poster

## Assessment of the Criteria to Practice Home Palliative Care

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**Background:** Whereas a high majority of French population should prefer Home Palliative Care (HPC) indeed dying at home, 57.9% French population die at health care center. In France Multidisciplinary Team specialised in Palliative Care (HPC Team) assess feasibility of HPC and support patient, caregivers and professionals.

**Aims and methods:** The survey leaded by a HPC Team in a rural area aims to identify the factors which influence HPC choice.

It was leaded by a retrospective non interventional method compounding in 2 phases :  
- elaboration of 65 factors according to the scientific literature and to a multidisciplinary focus group working at hospital or not.

-retrospective revue of 202 files or 514 situations (18months) assessed by the HPC Team. Univariate and multivariate statistics analysis are done.

**Results:** There is a distortion between generally accepted barriers by the professionals and the reality : lonely patients living, drugs unavailability outside hospital, terminal sedation necessity and rural areas living are not HPC barriers.

Caregivers HPC choice is as important as patient choice : 70% patients who which HPC but for whom caregivers refuse were hospitalised ; 69% patients who cannot give their opinion while caregivers prefer HPC stay at home.

Statistical analysis confirms barriers like patient, caregivers or professionals disagreement, symptoms unrelieved, but also the insecure feeling of patient or caregivers : 39% patients who feel insecure are hospitalised versus 24.5% who feel secure ( $p=0.001$ ) ; 53% patients whose caregivers feel insecure are hospitalised versus 12% ( $p=0.001$ ).

**Conclusion:** Beyond the evident requirement to HPC, this study question about the insecure feeling as a limit : HPC is an individualised project which limits are enounced by patient and caregivers themselves.

To improve HPC quality it is necessary to precise how evaluate the insecure feeling, what impact this feeling and also if HPC Team impacts this feeling.

**Abstract number:** P2-138  
**Abstract type:** Poster

### Hypercalcaemia in Palliative Care

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**Background:** Hypercalcaemia is the most common life-threatening metabolic disorder in cancer patients, and is defined by an adjusted serum calcium concentration of greater than 2.6 mmol/L. Hypercalcaemia occurs in around 10% of cancer patients. Tumour induced hypercalcaemia usually indicates widespread disease and a poor prognosis, with a median survival of 2–4 months.

**Methods:** Perform a retrospective audit of all patients admitted to the Marie Curie Hospice Glasgow, admitted during September and October 2013, by examination of patient medical notes and drug kardexs, use of data collection form and analysis of data in comparison to standard guidelines, to identify:

1. If malignant hypercalcaemia was anticipated in high risk patients (those with breast, lung, prostate cancers and myeloma)
2. That hypercalcaemia is managed according to guidelines
3. That serum calcium levels and serum urea and electrolytes (U&Es) were checked pre- and post-treatment.

**Results:** 44 out of 76 patients had their serum adjusted calcium level checked within 48 hours of admission

A total of 15 patients had raised serum adjusted calcium during the study period  
60% were male and 40% were female  
The median age was 64

The most common associated symptoms were **nausea and confusion**  
Post-treatment calcium and U&Es were only checked in 3 out of 9 patients treated  
30 day mortality rate was 60%

**Conclusion:** Hypercalcaemia is a relatively common problem in palliative care and must be treated according to the standard regional guidelines. Post-treatment follow up is important to determine if the treatment was successful or not.

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**Abstract type:** Poster

### Steroid Use in Palliative Patients in Plymouth, UK

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**Aims:** To establish whether palliative patients known to a UK hospice are prescribed steroids appropriately.

**Background:** Steroids are used frequently in palliative care, in an attempt to relieve specific and non-specific symptoms associated with advanced malignancy. Concerns have been raised regarding the 'uncontrolled' use of steroids in cancer patients, as patients are not closely monitored, allowing for the development of debilitating side-effects, often in the context of limited clinical benefit.

**Method:** Patients known to St Lukes Hospice from 1<sup>st</sup> November 2013 to 1<sup>st</sup> May 2014 (n = 1152), were highlighted. 384 had taken steroids.  
124 patients' online notes were analysed to establish which steroid they were prescribed, intended duration, start and stop dates, who prescribed them and why, and if steroid side effects were experienced.

**Results:** The most common steroid prescribed was dexamethasone 4mg. Steroid start date was documented in 63% (n=78) patients' notes. Reason for starting steroids was documented in 73% (n=90). 49% (n=61) died whilst taking steroids. 54 patients stopped steroids, stop date was documented in only 27 (50%).  
Who prescribed steroids was documented in 70% (n=87). Intended duration of steroids was documented in 14% (n=17). 48/124 patients (39%) experienced steroid-related side effects, most commonly peripheral oedema and proximal myopathy. Median duration of steroid course in the 49% (n=61) with start and stop dates, was 42 days (1–224 days).

**Conclusion:** Steroids are widely prescribed. There is insufficient documentation regarding steroid use, suggesting a lack of discussion, planning, and regular review. Many patients are left on steroids for too long, often experiencing undesirable side-effects. We need ensure awareness of patients' steroid histories. A 'Steroid Window' could be added to the online notes system. Regular review of this window could prompt clinicians to consider decreasing the dose or stopping steroids altogether.

**Abstract number:** P2-140  
**Abstract type:** Poster

### Early Palliative Care – “How Early Is Early Enough?” Significance of Specialized Palliative Care Provided Concomitantly with the First-line Chemotherapy after the Patients Were Diagnosed with Progressive Disease

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**Purpose:** Recently, some studies have revealed the efficacy of “early palliative care”, but the workforce of specialised palliative care (SPC) is limited. The scope of SPC must become more focused. The purpose of this study is to examine “how early is early enough?”

**Methods:** Subjects were patients who underwent chemotherapy for advanced cancer and died in palliative care unit (PCU) during last 2 years. Subjects who received regular SPC concomitantly with first-line chemotherapy after being diagnosed with progressive disease (PD) and then were transferred to PCU assigned to palliative care (PC) group. Subjects who were transferred to PCU after the discontinuation of chemotherapy were assigned to standard care (SC) group. We compared 1) quality of palliative care using Support Team Assessment Schedule, 2) quality of life using Good Death Inventory, 3) implementation rate of chemotherapy immediately before death, and 4) short-term mortality in PCU between these groups.

**Results:** Twenty-eight and sixty-three were assigned to PC and SC groups, respectively.  
1) PC group had significantly lower scores for physical symptoms control and patient anxiety

( $p < 0.001$ ). Communication among patient, family and medical professionals were significantly more favorable in PC group ( $p < 0.001$ ).  
2) PC group had significantly higher scores for “receiving sufficient treatment” and for “spending in their desired place” ( $p = 0.0008$ ,  $0.002$ , respectively).  
3) Implementation rate of chemotherapy 60 and 30 days before death were significantly lower in PC group ( $p = 0.041$ ,  $0.044$ , respectively).  
4) Short-term mortality ( $< 14$  days) in PCU was significantly higher in SC group ( $p = 0.0005$ ).  
**Conclusions:** Even if it is difficult to perform interventions “early after being diagnosed with cancer”, the feasible implementation of SPC concomitantly with first-line chemotherapy after the subjects were diagnosed with PD is expected to facilitate high-quality of palliative care.

**Abstract number:** P2-141  
**Abstract type:** Poster

### An Internal Audit into the Adequacy of Pain Assessment in a Hospice Setting in England, United Kingdom

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**Background:** Pain is the most common presenting symptom of patients referred to palliative services. The effective management of pain is therefore paramount to any palliative service. The SOCRATES mnemonic is a pain assessment framework that is widely used by healthcare professionals to help them to remember to ask about key questions concerning a patient's pain. The eight elements of this framework are Site, Onset, Character, Radiation, Associated Factors, Timing, Exacerbating and Relieving Factors and Severity.

**Aim:** To assess whether 100% of patients admitted to the hospice from and including 1st of February to 30<sup>th</sup> of April 2014 with pain as a symptom were fully assessed using all elements of the SOCRATES mnemonic. Furthermore to ensure whether these patients were written up for regular and breakthrough analgesia medication.

**Methods:** New admissions during the three months of February to April were identified using the in-patients admission record book. SystmOne™ (electronic medical record database) was then used to search for the patients that mentioned pain as a symptom and a score assigned according to the number of elements of SOCRATES used. The medications section on SystmOne™ was checked for the prescription of regular and breakthrough analgesia.

**Results:** The results revealed that 0% of patients were fully assessed using all elements of the SOCRATES mnemonic and 66.7% of patients were partially assessed. The mean average of SOCRATES elements used when assessing pain was 3.3. Regular and breakthrough analgesia were prescribed for 100% of patients who complained of pain.

**Discussion:** This hospice meets national standards for prescribing regular and breakthrough analgesia, however significantly falls below standards on the assessment of pain using all elements of the SOCRATES mnemonic. Further investigation could inquire into how this hospice compares nationally and internationally with other hospices and palliative services in the assessment of pain.

**Abstract number:** P2-142  
**Abstract type:** Poster

### Conditions in Off-label Prescription in a Unit of Palliative Care and Symptom Control (PCSC UNIT)

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**Background:** Off-label is used to refer the use of a drug outside the specifications of its marketing authorisation, including prescription for an unlicensed indication and/or administration by an unlicensed route.

Off-label medication use is about 20% of the commonly prescribe medications and in palliative medicine reaches 12–26%

A drug can be off-label in categories: drugs licensed by AEMPS for the given indication but in a different clinical situation, or by a different parenteral route, or not licensed by AEMPS for the given indication, although evidence of efficacy is available (literature based); drug which falls into the so called “gray zone” of evidenced based medicine, within which high-level evidence is difficult to reach even for treatments which are likely effective and Contraindicated.

**Aims:** Describe the use of “off-label drugs” in our Unit and to know which kind of category is the most frequent.

**Methods:** This study was taken during six months. A questionnaire was developed and were carried out by the physicians who attend the patients who were admitted in our Unit. Demographic and anthropometric characteristics, clinical background, current disease, and prescriptions were registered. Medications were analysed to determinate if they were off-label and in which condition.

**Results:** Of the 217 registered prescriptions in this survey, 39 were off-label (no marketing authorisation in 8 of them).

Studying each off-label indication we found that most of them are in the first category (when approval does not extend to cover the particular dose or indication, although evidence of efficacy is available), no one were contraindicated.

The prophylaxis of ulcer by proton pump inhibitors and the use of corticosteroids, buscapina, metoclopramide... were the most frequent.

**Conclusion:** In our clinical practice, off-label prescriptions are quite common (we never report in the clinical record that it is) in the belief that they will benefit patients who cannot be better helped with an alternative.

**Abstract number:** P2-143  
**Abstract type:** Poster

## Community Palliative Care Service Quality Improvement Project: Identification of Factors which Could Reduce Deaths Occurring in Hospital

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**Background:** Healthcare providers are facing increasing pressure to minimise the time patients spend in hospital and reduce the number of deaths that occur there. This is challenging due to limited resources and difficulties establishing which patients are likely to benefit from hospital treatment. Most people (97% of the general population) would prefer to avoid dying in hospital (British Social Attitudes survey May 2013), and more than two thirds of those with less than one year to live would prefer to die at home (Gomes B et al. 2012). Currently approximately 80% of patients known to our community palliative care service die outside hospital, a figure we hope to improve.

**Aim:** Our aim was to identify any common factors in patients known to the service who died in hospital which could be targets for intervention, to reduce hospital deaths further.

**Methods:** This was a retrospective case notes review of all patients known to the community palliative care service dying within the previous 4 months (March to June 2014).

**Results:** Themes suggest that the reasons for admission were complex, often unpredictable and related to an acute event. Key findings were that few patients had completed advance care planning (ACP) discussions, as compared to those dying at home. Only 1 patient had 'just in case' drugs compared to 100% of those dying at home. Also there was rarely contact between any attending healthcare professionals from other teams (e.g. the ambulance service) and the community team despite the availability of a 24 hour advice line.

**Conclusion:** In this group of patients some hospital deaths were unavoidable, related to an acute event, and admission may be appropriate for some individuals in their particular circumstances. ACP and enabling increased patients' contact our community service in acute situations will be targets for quality improvement projects in the next 6 months.

**Abstract number:** P2-144  
**Abstract type:** Poster

## Clinical Librarianship in a Hospice Setting. Can this Model of Information Support Be Beneficial to Clinicians at the Point of Care?

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**Background:** Clinical librarianship has been in existence since the 1970s. The role aims to support evidence based patient care and clinical decision making at the point of need. There is no one fixed model of clinical librarianship. There is currently no published research on clinical librarianship within a hospice setting.

**Aims:** To trial a clinical librarian service at Sue Ryder Leckhampton Court Hospice, Cheltenham, UK to discover whether the service would benefit patient care and how the library service could develop further.

**Objectives:** To determine:

- The impact on patient care and
- Whether the service supported clinicians' information needs
- The most appropriate service model
- The impact for Gloucestershire Hospitals NHS Foundation Trust Library Services

**Methods:** The pilot ran from May to July 2014 and entailed a librarian attending admissions meetings and ward rounds with the hospice doctors to ascertain what information related help could be given.

**Results:**

- 9 literature searches were completed on patient care and service improvement projects
- The librarian met with different hospice staff, appropriate information services were provided.
- The library service gained an understanding of the hospice setting and operation
- Understanding there is not always evidence to support treatments so a 'this usually works' method is used frequently in palliative care
- Increased awareness of library services amongst hospice staff

**Discussion:** The evidence base around palliative care is not always as robust as in other medical specialties – therefore the role of clinical librarian has to be altered accordingly. A service in this particular format was found to be too time-consuming for the library service and the clinical benefit was limited. Hospice staff could be equally well supported with a remote service via email or telephone. A close relationship between Sue Ryder Hospice and the library service should be maintained to support evidence based patient care.

**Abstract number:** P2-145  
**Abstract type:** Poster

## Supporting Care in the Last Days of Life: An All-Wales Approach to Shifting Gear

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Recent publicity around the Liverpool Care Pathway (LCP) in England led to the Neuberger Enquiry and the subsequent recommendations for care in the last days of life from the work of the NHS Leadership Alliance. Within Wales the LCP was never mandated: instead we have implemented and centrally supported the Welsh Integrated Care Priorities for the last days of life (WICP).

Although the WICP has been continually monitored via variance reporting and audited annually, we have limited conclusive evidence to support its continued use as the best model of care. The WICP represents a process-model approach to delivering care in the last days of life however, the current clinical climate is geared towards a person-centred approach, as described by the outputs of the Leadership Alliance. A critical review of the WICP indicated the need to change in step with this change in focus.

Through a process of wide consultation across the principality a new system of guidance for

supporting care in the last days of life has been agreed. The process of implementation is built on the foundations established by the WICP and locally identified champions will be leading the work. A 'top-down, bottom up' approach has been adopted involving Local Health Boards and healthcare professionals with direct patient contact. The change process is being centrally monitored and supported on a Wales-wide basis. The changeover will be completed by April 2015 and we expect to report on the barriers, lessons learnt and success stories.

**Abstract number:** P2-146  
**Abstract type:** Poster

## Anticipatory Prescribing in Palliative Care

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**Objective:** To assess the prescribing of end of life (EoL) medications on Y Bwthyn Newydd (YBN), a palliative care ward in Princess of Wales Hospital Bridgend, in patients who had not been placed on the All Wales Integrated Care Priorities (ICP).

**Methods:** Retrospective audit of notes of patients who passed away over a two-month period (01/09/13 – 02/11/13) on YBN. Where it was documented that the patient had been started on the ICP, they were excluded from our data. EoL medications were defined as a subcutaneous (S/C) anxiolytic, anticholinergic, analgesic and antiemetic, as per the prescribing 'goals' targeted by the ICP.

**Results:** Overall, 8 of the 14 (57%) investigated had all four keys areas of prescribing done. For the individual elements of the prescribing, 14/14 had an anxiolytic, 13/14 had analgesia, 11/14 had an anticholinergic and 11/14 had an antiemetic prescribed. When excluding patients who died unexpectedly or within 24 hours of admission, this percentage rose to 80% (8/10).

**Discussion:** In the most recent ICP review, a rate of 95% (n=242) was achieved for patients on the ICP (target is 100%), therefore our data raises the question of whether we are giving the same level of care to palliative patients who are not placed on the ICP prior to death. We could consider Targeted Anticipatory Prescribing in the hospital setting, given patients on YBN do have the potential to deteriorate rapidly. Due to the small number of cases, a larger scale audit could be used to provide more reliable data.

**Abstract number:** P2-147  
**Abstract type:** Poster

## Comparison of Anticipatory Care Planning in Lung Cancer, COPD and Nursing Home Populations Admitted to the Acute Inpatient Setting

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**Background:** Anticipatory Care Planning (ACP) is increasingly used in many specialties for people with malignant and non malignant life-limiting diseases.

**Aim:** The aim of this audit was to compare the use of ACP in patients with incurable lung cancer, COPD and Nursing Home residents who were admitted acutely.

**Method:** Over 4 weeks the documentation of all patients admitted to an Acute Medical Unit (maximum of 20 per category) who had incurable lung cancer, severe COPD (as per pre-defined criteria) or nursing home residents were audited. A checklist was created to assess if patients had any evidence of ACP (DNACPR, Key Information Summary, ...) on admission and throughout their admission. Patients were followed up until discharge or death.

**Results:** 37 patients were identified. 85% were deemed eligible for ACP. Of these, 40% had ACP before admission and 20% had new ACP completed during admission. Of the 21 patients who had ACP only 12 had this communicated back to the community team on their discharge letter. There was an in-hospital mortality of 22% in the Nursing home population and 15% in the COPD population. No lung cancer patients died in hospital.

	Nursing Home Resident	Severe COPD	Incurable Lung Cancer	Total
<b>No. of Patients</b>	18	13	4	35
No. Appropriate for ACP	17	9	4	30
ACP before Admission	9	3	2	14
New ACP during Admission	3	2	2	7
ACP communicated at discharge	8	3	1	12
Specialist Services Pre-admission	1	11	2	14
Died During Admission	4	2	0	4
No of deaths at 6months	7	3	3	13

[Results]

**Conclusion:** Despite the majority of these patients being appropriate for ACP, little active ACP took place whilst in hospital. This may reflect a lack of clinicians' knowledge, confidence or time pressure. Education and raising awareness of the benefits of ACP may encourage discussions with both patients and families in both hospital and the community. No Funding Received



**Abstract number:** P2-148  
**Abstract type:** Poster

## Models of Hospital-based Specialized Palliative Care in Austria

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**Background and aim:** Palliative care units (PCUs) in Austria are mainly located in urban areas. To maintain palliative care in rural areas a model of hospital-based specialised palliative care was formed. In contrast to independent PCUs these integrative palliative units (IPUs) are affiliated to other departments in hospitals who share the staff and resources with them.

The aim of this questionnaire-based pilot study was to collect first descriptive data from these IPU's.

**Material and methods:** After four in depth interviews with palliative care specialists and a literature review two questionnaires were designed, one for physicians with 25 questions and one for nursing staff with 20 questions. Topics contained general data, training in palliative care, infrastructure and resources. 9 Austrian hospitals offering IPU's were found and the questionnaires were sent to them in July 2014 with the request to hand it to the personnel involved in the care of palliative patients.

**Results:** All 9 included hospitals returned questionnaires. In total we received 96 questionnaires, 80 questionnaires from nursing staff and 16 questionnaires from physicians. Seven out of the 9 "IPEs", were installed in the last 3 years. 6% of the physicians and 31% of the nursing staff are responsible exclusively for palliative inpatients. 37% of the physicians were able to use all the planned working time for the care of palliative patients.

**Discussion and conclusion:** The response rate of the questionnaires shows a high level of interest. IPU's seem a warranted model to increase specialised palliative care in Austria with the benefit to optimise resources and embed the idea of palliative care in hospitals without PCUs. More governance, perhaps through interaction with PCUs or networking groups and definition of training standards for employees seem necessary to achieve high quality of care in patients with life limiting illness and complex, challenging needs in Austria.

**Abstract number:** P2-149  
**Abstract type:** Poster

## Patient Experience of Community End of Life Care Informs County-wide Improvement Programme

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**Background:** One large organisation provides all the generalist and most of the specialist palliative care in the community in the county and was integrating them into locality teams. A 3 year improvement programme was being developed to achieve draft organisational End of Life Care (EoLC) aspirations.

**Aim:** To establish current strengths and weaknesses of existing community EoLC services across the county in order to prioritise improvement.

**Method:** Ten National Voices "I statements" designed to measure person-centred, coordinated care were chosen to match the draft EoLC aspirations and put into a postal questionnaire. This was sent with a named letter from the Chief Nurse to 296 random community patients who were identified as living their last year of life one day in March 2014. They were asked to reply based on their experience of community nursing and therapy services.

**Results:** Mean age of the 296 patients was 74 (22–98), 169 (57.1%) had cancer, 29 (9.8%) respiratory disease and 24 (8.1%) neurological disease. 133 (44.9%) questionnaires were returned-70 (53%) completed by patient, 45 (34%) by carer, 18 (14%) unknown. No statement had less than 50% agreement. The statements with most agreement were "All my needs as a person are assessed" (80%) and "I have the information that I need to make decisions and choices about my care and support" (78.9%). The statements with least agreement were "I always know who is coordinating my care" (57.9%) and "My carer/family have their needs recognised and are given support to care for me" (63.9%).

**Conclusions:** Patients and carers have informed our organisational priorities for improvement. The two weakest areas are

- assessment and support of family/carers and
- coordination of care.

These are both now separate work streams within the internal improvement programme. The questionnaire will be sent annually to monitor outcomes.

The good response rate suggests patients in the last year of life are willing to inform community service improvements.

**Abstract number:** P2-150  
**Abstract type:** Poster

## Audit of Documentation of End of Life Care Priorities in Patients under Local Hospice Services

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**Background:** Although majority of patients in UK want to die at home, about 50% die in Hospital. Many Hospices and clinical commissioners consider achievement of preferred place of death as a quality marker for the palliative care service. Studies show formal recording of preferred place of death, improves the chance of achieving it.

**Aim:** This audit was planned to check the documentation levels of aspects of preferred place of care, preferred place of death, Resuscitation. We also included the documentation of carer's preferences as well.

**Methods:** At our Hospices, electronic case note system (inflex) is used to record preferred place of care (PPoC), Resuscitation status (DNAR) and preferred place of death (PPoD). We checked the above aspects on 15 inpatients (IPU) and 15 Home care team patients (HCT) and 15 day therapy patients (DTU). Those patients seen at least 3 times by the professionals

only included as some occasions might not be appropriate to discuss these on the first review.

**Results:** The majority of patients from DTU and HCT had their first preference for place of care recorded on the system (14/15 of HCT, 12/15 DTU). Only 10/15 IPU patients had this recorded. Hardly any patients had their second choice of place of care recorded on the system. (2/45). The majority of HCT and DTU patients had their first choice place of death recorded on Inflex (13/15 and 11/15), however only 60% of IPU patients did (9/15) making 33/45 in total. Only around 7 out of 45 patients had their second preference place of death recorded. Preferred place of death was achieved by 60% of IPU patients, 80% of HCT patients and 70% of DTU patients who had died according to the information. DNAR status was completed in 42/45. ACP discussion was not recorded in the majority of patients seen by IPU and HCT.

**Conclusion:** The audit showed areas of good practice and also some need for improving of recording of these important indices. This was presented to the teams and further audits planned.

**Abstract number:** P2-151  
**Abstract type:** Poster

## Audit of Usage of Steroids in an Inpatient Hospice Patients against Local Guidelines

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**Background:** Steroids are widely used in palliative care for a variety of indications. However, they are associated with significant side-effects and for this reason should be used with care. Their use should be reviewed on a frequent basis to ensure patients are receiving the minimum effective dose for the minimum required time.

**Method:** Retrospective drug chart and case notes review. March 2014–October 2013.

**Results:** Out of 48 identified, 24 were inpatients. 24 patient notes & drug chart was analysed from electronic notes. 17 patients out of 24 were admitted on steroids and 7/24 was started as inpatient. Dose was documented clearly in all patients, 17/24 had appropriate dose per their indication. 3 had unclear and 2 was not applicable and 2 had lower dose for their indication. Duration was documented in 14. 11/17 had clear documentation of who started the steroids (the admitted on steroids group). 9/17 had documented benefits and 7/17 -no clear documentation of the benefits. The data analysis on those who were started on Steroids (7)- All had indications identifiable and all had PPI started; 2/7 had identifiable evidence of check of blood sugar. All had evidence of review of steroids. Those patients who were discharged from Hospice on dexamethasone- 2/8 had clear plans and 4/8 had evidence of review after discharge. One had dexamethasone during the admission, but not mentioned in the discharge letter.

**Recommendation:** We conclude that those who have steroids started as inpatients have indication, review, and plans documented better than those admitted on steroids. However, those who were discharged on steroids lacked in documentation of plan in their discharge letter resulted in lack of follow up. We recommended Improved documentation of duration, dose, started by, benefits, side effects on admission and those who are started. Document plan, review of benefit, side effects, dose in daily review, Document a clear plan for steroids in the discharge letter and Repeat audit in 1 year.

**Abstract number:** P2-152  
**Abstract type:** Poster

## Development and Preliminary Evaluation of a Complex Intervention on Pain Management in Hospitalized Cancer Patients

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**Background:** Despite the availability of effective assessment procedures and treatments, unrelieved pain in hospitalised cancer patients remains a problem. Many interventions were suggested, without achieving satisfactory results.

**Aims:** This study was retrospectively set up from a quality improvement programme implemented by a hospital Palliative Care Unit (PCU). It concerns the development and preliminary assessment of an intervention aimed at improving pain control in hospitalised cancer patients.

**Methods:** This study can be interpreted as a Phase 0–I, according to the MRC Framework for the assessment of the complex interventions. It includes a literature review on interventions for pain management and the identification of the potentially effective components of the interventions. According to the results of the previous steps a new quality improvement intervention was developed, piloted and preliminary assessed in an Oncological ward.

**Results:** No effective interventions were identified. Five potentially effective components were identified: professional training, daily screening of pain, patient education, specialist PCU consultations, and support from the Hospital Management. The Programme was implemented on the ward throughout 6 months. 75% physicians and 88% nurses participated in the training. After the implementation, daily screening of average pain was performed on 59% of patient-days, and 33% of the patients received the leaflet on cancer pain. All patients with severe pain were referred to the PCU for consultation. The outcome assessment showed 19.3% of patient-days with moderate pain, and 2.6% with severe pain. An external audit was performed by the Hospital Management at 9 months from the end of the intervention.

**Conclusion:** Results support the feasibility of the intervention and of the its five components. Further studies are needed for assessing the effectiveness of this complex intervention.



**Abstract number:** P2-153  
**Abstract type:** Poster

## The Use of Medications in the Last 24 Hours of Life in the Acute Hospital Setting – A Descriptive Comparison of Cancer and Non Cancer Patients Using Data from the National Care of the Dying Audit Hospitals – England (NCDAH) 2013/14

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A national audit of care in the last hours or days of life was undertaken in the acute hospital setting in England (NCDAH 2013/14) involving 149 sites and 6,580 cases. International consensus exists for the use of 4 key drugs and the use of continuous subcutaneous infusion (CSCI) has been advocated in support of patient comfort at this time. In Round 2 of the NCDAH (2008/9) 54% of all patients had CSCI prescribed, of these 1026 had a diagnosis of cancer (67% of all cancer patients) and 1080 were non cancer patients (46% of all non cancer patients).

**Aim:** To explore the use of CSCI and any similarities and differences for cancer and non cancer patients in the use of CSCI in the last 24 hours of life, including medications and dosages used.

**Method:** Consecutive, anonymised, retrospective case note review of the last 'episode of care' including deaths during May 2013 (excluding acute/sudden/unexpected). Drugs given via CSCI in the last 24 hours of life, combinations and doses, were analysed descriptively via SPSS.

**Results:** CSCI prescribed for 1850 (28%) cases. 722 (46% of all cancer patients) had primary cancer diagnosis, 1128 (22% of all non cancer patients) were non-cancer patients. Non-cancer patients were older (83 vs 74) & had recognition of 'dying' earlier (75 hours vs 62 hours prior to death).

The 4 key drugs were regularly prescribed.

Most (both groups) received 2/3 drugs

Most common 2 drug combination – sedative (usually Midazolam) & opiate (usually Morphine).

Median dose sedative: Midazolam (both groups) – 10mg over 24 hours

Median dose opiates: Morphine – cancer 15mg, non-cancer 10mg; Diamorphine – cancer 12.5 mg, non-cancer 10mg; Oxycodone – cancer 20mg, non-cancer 10mg.

**Conclusion:** Overall, the use of CSCI is around half of that in 2008/9 but in line with this audit patients with cancer are still more likely to die with a CSCI in place. Type of drugs administered was similar in both groups, but the dose of opiates for non-cancer patients was lower on average.

**Abstract number:** P2-154  
**Abstract type:** Poster

## Audit on the Use of an Individualised Care Plan for the Last Days of Life in an Acute Hospital Setting

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**Background:** The National Care of the Dying Audit for Hospitals, England, shows that major improvements need to be made for better care of the dying and support for their families. In response to guidance from the leadership alliance of care of the dying people, Basildon and Thurrock University Hospital (BTUH) implemented an individualised care plan (ICP) for the last days of life in March 2014. This audit was modelled on the national care of the dying audit.

**Aims:**

- 1) To identify if there is any difference in documented decision making and communication with a different approach in end of life care (pathway versus individualised care plan).
- 2) To benchmark care using ICP against national standards.

**Methods:** Questionnaire used in the national care of the dying audit was adapted to facilitate data collection. BTUH audit department uploaded this questionnaire into survey monkey which automatically analysed the data. Data was collected from 1<sup>st</sup> to 30<sup>th</sup> Sep, 2014. The questionnaire was completed by two palliative care team members. Inclusion criteria were: age > 16 yrs, expected death, all adult inpatients of BTUH. Exclusion criteria were: age 16 and below, sudden death, death in community, pediatric wards.

**Results:** There were 96 deaths in the month of September. Data will be analysed for these: % expected death, diagnosis, % of expected death on ICP, % of expected death with Preferred Priorities of Care (PPC) in place, % of patients with discussions and decisions around clinical nutrition and clinical hydration in place at their end of life.

**Conclusion:** Individualised care plan (ICP) is a care plan for individual patient at their end of life. It results in clear documentation of discussion and decision making around all aspects of end of life care. ICP can be used as a benchmark for care of the dying patients.

**Abstract number:** P2-155  
**Abstract type:** Poster

## 'Palliation in the Hospital' – A Quality Improvement Project

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**Background:** It has been documented that palliative patients in Denmark have unmet needs and dying during admission can be a frustrating experience for patients and relatives. A survey in our hospital documented that health care professionals had a felt need for improving their skills in palliative care.

**Aim:** To improve the quality of palliative care in our hospital. Methods A 1-year classical quality improvement project was conducted in a medical ward, including patient record audits and a survey of the involved professionals before and after the project period. Based on the results a generic model was developed and implemented over a period of 4 year period in the departments of: Oncology, Haematology, GI-surgery, Neurology and Urology:

**Content:**

- A specialist palliative care project nurse was present in the wards to facilitate and support

the implementation during a 10 months period

- Multi professional seminars, teaching and training sessions
- Mono professional teaching and support to doctors by SPC consultant Structure
- Guidelines were made available electronically.
- Checklists and standard phrasing texts were integrated in the electronic patient record:
- EORTC-QLQ-PAL15
- Optimal discharge of patients to home
- Optimal care the last days of life for dying patients

**Monitoring:** Baseline, halfway and end audit of patient records

**Results:** 230 patient records were audited in the five year project period. There was an overall improvement in the audited areas, but still with potentials for improvement, which were lined out to the management in a report at the end of each project with proposals for further improvement.

**Discussion:** We believe this project has been a starter for a continuing change process in our hospital: EORTC-screening is used frequently, wards have designated 'palliative care nurses', a PC network has been established across the hospital, the electronic PC guidelines are available for all the hospital.

**Abstract number:** P2-156  
**Abstract type:** Poster

## Audit of the Use of Subcutaneous Fluids by a Community Palliative Care Service over a 6 Month Period

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**Background:** Subcutaneous fluid (SCF) infusion may be used to provide symptomatic relief of thirst in a patient unable to swallow, and as a means of rehydration.

The patients are assessed by a doctor to be suitable for the administration of SCF, which are then prescribed. 1 to 2 litres of infusion fluids may be given over a 24-hour.

**Method:** The electronic notes of all patients who had subcutaneous fluid in a six month period from the 1<sup>st</sup> of January 2014 were reviewed. Clinical and demographic data extracted included diagnosis, assessment, number of infusions given, and outcome.

**Results:** Over this 6 month period 29 infusions were administered, to 8 patients. 5 females and 3 males. (6 cancer, liver failure, an oesophageal pouch). Number of treatments ranged 1–8.

In all cases 500mls of normal saline was administered on a daily basis. All patients were reviewed by a doctors prior to the first infusion, and fluids were prescribed. Trust policy and procedure was followed.

Ages ranged from 61–91 y.o old (70).

Indications for the fluids: 3 difficulty swallowing, 4 symptomatic thirst, and 1 vomiting.

**Outcome of receiving fluids:** In 4 cases given to relieve symptoms in the terminal stages of the disease.

The 3 cases infusions was given and patients, were then able to resume drinking.

1. patient had an oesophageal pouch, 8 infusions were given while she was being assessed by the hospital for PEG insertion.

**Discussion and conclusion:** No adverse effects of the fluid were reported, and the Trust policy was adhered to.

In 3 cases the infusions relieved symptoms and avoid hospital admission. The patient who was awaiting PEG insertion had investigations as an outpatient and then proceed to PEG insertion. The 4 cases who received infusions in the terminal stage of these disease, had documented symptomatic relief from the infusions.

The use of subcutaneous fluids in this audit relieved symptoms and did not lead to any adverse effects. Trust policy was followed in all cases.

**Abstract number:** P2-157  
**Abstract type:** Poster

## A Regional Study of the Management of Delirium amongst Hospice Inpatients in the North-East of England

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**Aim:** Delirium is known to be associated with significant patient morbidity and mortality.

NICE have issued clear guidance on how to manage delirium. However, adherence to guideline recommendations is poor and we believe that this represents an important opportunity to improve patient care.

**Method:** All patients admitted to one of five hospices in the North-East of England, over a 5 month period, were screened for delirium using the short-CAM tool. The notes of short-CAM positive patients were then analysed to determine how they had been managed.

**Results:** 57 of 298 patients were identified as having delirium (19%). 3 of these patients were excluded due to missing data. A reversible cause was considered in 45 out of 54 patients (83%). Non-pharmacological interventions were used in 15 out of 54 (28%). Pharmacological intervention was used in 31 patients (57%). The pharmacological intervention most commonly prescribed first line was benzodiazepines, in 21 out of 31 patients (68%). First-generation anti-psychotic drugs, such as haloperidol, were used first-line in 10 patients (32%).

**Conclusion:** Recommendations put forward by NICE suggest that non-pharmacological interventions should be used first-line to treat patients with delirium. Amongst our patient cohort, non-pharmacological interventions were only used in 28% of cases. When pharmacological management is required then the guidelines recommend use of 1<sup>st</sup>-generation antipsychotics, such as haloperidol. Our data showed this only to be the case in 32% of patients. Benzodiazepines can worsen delirium and increase the risk of falls, but these drugs were used first-line in 68% of patients. Our data shows that patients with delirium are not being managed in accordance with NICE guidance, which may reflect suboptimal staff education. Further work is required to develop effective staff education initiatives.

## Basic and translational research

Abstract number: P2-158  
Abstract type: Poster

### Relationship between Cytokine Concentration in Ascites and Effects of Cell-free and Concentrated Ascites Reinfusion Therapy (CART)

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**Background:** CART (Cell-free and Concentrated Ascites Reinfusion Therapy) is now attracting rising attention in Japan as one of important strategies for symptom-relief against malignant ascites. We have already reported its favorable effects on symptom relief.

**Aims:** The aim of this study is to evaluate cytokine concentration in original ascites and its effect on survival after CART procedure.

**Methods:** From April 2011 to March 2013, CART procedures were performed on 43 patients (gastric cancer: 28, ovarian cancer: 6, pancreatic cancer: 5, and cancers of other origins: 4) at our hospital. In the first session of each patient, the concentrations of inflammatory and regulatory cytokines including IL-1 $\beta$ , IL-6, IL-8, IL-12, TNF- $\alpha$ , and IL-10 were measured in original ascites using BD Cytometric Beads Array System. We evaluated their relation to the side effects of CART and to patients' survival after CART procedures.

**Results:** IL-6, 8 and 10 were detected at relatively high concentration in original ascites (IL-6:  $1.56 \pm 8.51 \times 10^4$  pg/ml IL-8:  $5.10 \pm 6.69 \times 10^2$  pg/ml IL-10:  $1.63 \pm 2.22 \times 10^1$  pg/ml). The degree of body temperature elevation, one of the major side effects of CART, was correlated with the concentration of IL-6 and 8 significantly (IL-6:  $p=0.025$ , IL-8:  $p=0.022$ ), although the elevation itself was not clinically significant. Survival of the group in which IL-10 was detected in ascites was significantly better than the group in which IL-10 was not detected. Median survival was 115 days and 51 days for detected group and not detected group, respectively ( $p=0.026$ ).

**Conclusions:** We conclude that ascitic concentration of IL-6, and 8 correlated with elevation of body temperature after CART, and existence of IL-10 in ascites related to longer survival. Origins and clinical significance of these cytokines still remain to be elucidated.

Abstract number: P2-159  
Abstract type: Poster

### Assessing the Needs of Patients in the Palliative Home Care Setting: Can We Do Better?

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**Background:** In the provision of palliative home care, some patients require more resources than others. The 10 most contacted patients, out of 85 (June 2014), accounted for 30% of total contacts made.

**Aim:** To identify and classify the needs of patients who require more resources and devise strategies to optimise resource allocation.

**Method:** In a 3 month period from 1/3/14 to 31/5/14, the 10 patients who called in the most to the service (incoming phone calls) and who required the most number of unplanned home visits were identified. Case notes from these patients were analysed to extract the underlying needs relating to the phone calls and home visits. These needs were then classified into categories which included medical advice, procedural, high anxiety and social support requests.

**Results:** All 10 patients received palliative care for cancer related diagnoses, and were predominantly Chinese (80%). For each patient contact (incoming phone call or unplanned visit), 1 or more needs were identified. There were a total of 94 incoming phone calls and 35 unplanned home visits, making a total of N=129 patient contacts.

86% of the contacts were associated with requests for medical advice. Uncontrolled pain (13%) and fever (7%) were frequently encountered medical problems. 7% of contacts were related to anxiety.

17% of contacts were for procedural requests, 9% for patient updates, 6% for home visit requests, 6% for social support, 2% for renewal of medication scripts and 2% for the transport authorisation of controlled drugs.

**Conclusion:** Our study identified requests for medical advice as the major reason for patients calling in to the service or for a home visit. Pain and fever were the most common medical situations dealt with. Strategies to optimise resource allocation could take the form of patient education materials relating to pain and fever. Steps to pre-emptively allay patients' anxiety may also be useful to reduce resource utilisation in our service.

Abstract number: P2-160  
Abstract type: Poster

### The Distraint Masculinity

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Dying is a gendered situated experience. Relatively few discussions about death and dying have looked beyond patient perspective in relation to culture and images of men and masculinity. Despite a growing body of literature on dying, critical studies about men and

masculinities in relation to this is needed.

**Aim:** The aim was to describe the perceived and self-reflected processes of dying in relation to gendered ideas of culture, family and identity.

**Methods:** We used a narrative thematic approach to analyse 8 interviews conducted over 18 months with one man close to death.

The analysis focuses on the interplay of death and dying and examines how they can be related to the concept of hegemonic masculinity and the processes connecting such men with the position of being.

**Result:** Three themes are presented here: The priorities – straightened, the body – revised, the fatherhood – comprised. Setting the priorities straight when time was meted out entails revising norms connected to work and what it means to be a "real" man. The navigation towards child-centered manhood represents instant re-evaluation of work. The presence of body is a deeply rooted foundation in perceptions and ideas of masculinity. Hence, the body is often regarded as a machine, i.e. working and operating in social situations, and bodily decline is a dispossession of masculinity. Achieving the goal of a "positively involved fatherhood" indicates that the amount of involvement matters in contemporary masculinity. Being present seems to involve a range of responsibilities, such as economy, practical and emotional strings even beyond death.

**Conclusion:** The overarching "distraint masculinity" uses images and ideals as tools to reach last possible opportunities for fulfillment rather than filling a function as a style and posing in gendered meanings, covering strategies of: concentration as in putting priorities right, dispossession or loss due to bodily decline and, extension of responsibilities beyond death.

Abstract number: P2-161  
Abstract type: Poster

### Biological Changes towards the End of Life: A Feasibility Study

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**Background:** Diagnosing when someone is in the last hours or days of life is an ongoing difficulty for clinicians. Although few studies have specifically investigated biological changes during this time.

**Aim:** To assess the feasibility of collecting biological samples from patients towards the end of life, and analysing these samples using systemic research approaches.

**Method:** A feasibility study collected serial urine samples from patients towards the end of life in a Hospice in the North of England. Urine that was collected from consenting patients who subsequently died during the study was then analysed. Two systemic research approaches were then used to analyse the urine.

A metabolomic approach; analysing volatile organic compounds (VOC) by Gas Chromatography Mass Spectrometry.

A genomic approach; global genome methylation was assessed by determining the DNA methylation of LINE-1 retrotransposable element by Pyrosequencing. Regional promoter hypermethylation was assessed by quantitative methylation specific PCR (qMSP).

**Results:** During the 12 week feasibility study a total of 128 separate samples from 20 different patients were collected. 56% (n=58) of inpatients at the hospice were approached, with a consent rate of 57% (n=33). Of the 43% who did not consent; 17% of those approached became unwell, too fatigued, lost capacity, died or were discharged home; 26% of those approached refused, usually these patients had distressing pain, low mood or profound fatigue. Seven people died while the study was ongoing, and another 4 patients died in the following 4 weeks.

Results from the VOC and genomic methylation studies of the urine samples will be presented at conference.

**Conclusion:** It is possible to collect biological samples amenable to systemic analysis from patients towards the end of life. Research into the biological changes at the end of life could develop a greater understanding of the dying process, which may lead to improved diagnostics and care.

Abstract number: P2-162  
Abstract type: Poster

### Palliative Care for People with ID in Europe

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**Background:** Due to the increasing longevity over the last decades people with intellectual disabilities (ID) are likely to die over a prolonged period of time because incurable, chronic illnesses occur more frequently in old age. Therefore there is a growing need for high quality Hospice and Palliative Care for people with ID. But so far, supported data on dying and death of people with ID and the quality of palliative and end-of-life care for people with ID within European countries is not available.

**Aim:** The aim is to monitor dying and data on death, processes and quality of end-of-life care for people with intellectual disabilities.

**Method:** An international exploratory workshop brings together academics and professionals from a range of countries in Europe to discuss and debate practical research issues. The objectives of the exploratory workshop are

- 1) to share experiences from a range of countries on collecting dying and death data about people with intellectual disabilities, including the practical and ethical issues faced whilst doing so,
- 2) to agree a set of definitions and benchmarks that will support internationally comparable data relating to death, dying and quality of Hospice and Palliative Care for people with ID to be collected and that is of relevance to policy-makers and practitioners, and
- 3) to develop the framework for a European research project on Hospice and Palliative Care for people with ID.

**Results:** The international exploratory workshop advance research into dying, death and the quality of Hospice and Palliative Care for people with intellectual disabilities. It allows us to make inferences at national and international levels that will support the development of practical strategies to address common concerns identified by the data. First results of the international exploratory workshop will be presented.

**Abstract number:** P2-163  
**Abstract type:** Poster

## Volume of Distribution of Opioids Administered in Humans Can be Estimated by Electric Charge under Biological pH Conditions – Consideration of how to Predict the Pharmacokinetics from the Structural Formula of Opioids

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**Introduction:** Steady-state volume of distribution (Vdss) is one of the most important pharmacokinetic profiles for administration planning of medications including opioids. Understanding the relationships between Vdss in opioids and physicochemical properties calculated from chemical structures of the drugs gives quite useful information to estimate opioids that have limited pharmacokinetic information. Therefore, we used a technique of quantitative structure–pharmacokinetics relationship (QSPkR) analyses to gain the knowledge for the relationships. That is, the physico-chemical properties of a variety of opioids were computed based on the chemical structures as chemical descriptors by using methodology in the field of chemoinformatics, and significant chemical descriptors related to Vdss were researched. Furthermore, such relationships were applied to construct Vdss-prediction models.

**Methods:** Twenty six kinds of Vdss-known opioids were selected in databases such as Metabolism and Transport Drug Interaction Database and investigated in the present study. Many physico–chemical properties were estimated by computational techniques based on the chemical structures of opioids by using chemical structure operating software such as MarvinView and Molecular Operating Environment (MOE), and then relationships to Vdss were studied.

**Results and discussion:** A result showed that properties of electric charges of opioids under biological conditions around pH7.5 were found to significantly correlate with Vdss as the most important molecular property. This finding will be useful to predict Vdss in opioids without pharmacokinetic information such as new-medication candidates, active metabolites of opioids, and illegal narcotic drugs.

## Bereavement

**Abstract number:** P2-164  
**Abstract type:** Poster

### Bereavement Support after Patient's Death at a Palliative Unit

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**Background:** As one of the palliative care foundation is bereavement support to family and other loved ones in their bereavement. Some persons need more support than the network can give and need expanded support. The Palliative Unit at Sahlgrenska University Hospital has developed a method for bereavement support.

**Aim:** To provide bereavement support to family and other loved ones after the death of a patient and to evaluate those who need support from other professionals.

**Method:** The social worker at the Palliative Unit is responsible for the bereavement support to the loved one after a patient has died at the Unit. The social worker have a conversation with a family member or another loved ones close to the patient's death. For those who need more support immediately after the death, are offered further support from the social worker. If there is no need for immediate support the social worker take a second contact often by telephone after 6 – 8 weeks. If there is need for support beyond that, the social worker continues with the support or refer to other bereavement care, depending on the problem.

**Result:** This method has been ongoing for a decade and give a structure to the bereavement support. The method opportunity to early identify those who have more needs for special bereavement support.

The bereavement support conversation embrace four areas. The question are intertwined in the dialogue and is not like a questionnaires:

How does the bereavement process progress?

Is there any medical questions left?

Which support from the network is available for the bereavement person?

Estimation of further need for support and if necessary a referral to psychiatry, church, primary care is sent.

**Conclusion:** It is important that the support is given in an individual way. Also it is important that the support is given by a professional who have the time to meet the bereavement person and who have competence and knowledge of grief and level of bereavement treatment.

**Abstract number:** P2-165  
**Abstract type:** Poster

### "Support Is too Fragmented": The Bereavement Needs of Carers and the Presence of Prolonged Grief Disorder

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**Background:** The necessity of assessing and meeting family carers' needs during end-of-life care and into bereavement is widely acknowledged, but less attention has been paid to the estimated 10% of family carers experiencing bereavement who develop 'Prolonged Grief Disorder' (PGD). PGD, typically formally diagnosed six months post-bereavement, involves a markedly intense reaction to a loved one's death. Symptoms include difficulty accepting the loss, bitterness, numbness, identity disorientation and a feeling of being stuck in grief.

**Aims:** To explore the experience and awareness of bereavement support and PGD with carers and health/social care professionals

**Methods:** A mixed methods study was undertaken. Two focus groups were conducted with carers (n=16) and an online survey administered to a range of health/social care professionals involved in the care of people at the end-of-life (n=59). Thematic analysis of focus group transcripts was undertaken and descriptive statistics used to illustrate summary data from the online survey.

**Results:** Our focus group data indicate varying challenges experienced by carers and the need for appropriate pre and post-bereavement support to be provided in order to facilitate a healthy grieving process. Survey data reveal that health/social care professionals were uncertain of the most appropriate course of action to pursue to support carers facing bereavement. Forty (68%) respondents indicated that bereavement-related support could be improved; 24 (42%) respondents had encountered family carers they considered were experiencing PGD; 38 (68%) respondents did not feel able to accurately predict future cases of PGD.

**Conclusion/discussion:** Our data suggest bereavement-related support for carers could be improved, that PGD may be experienced at a higher level, in some populations, than previously supposed and that health/social care professionals face difficulties in reliably identifying the risk of PGD amongst carers.

**Abstract number:** P2-166  
**Abstract type:** Poster

### The Psychosocial Management of Health Care Professionals towards the Imminent Death of Terminally Ill Patients

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**Background:** Death is a multidimensional phenomenon including physiological, psychological, and spiritual dimension of human nature. The process of death is a loss not only for the patient and family, but also for doctors and nurses. The reactions to this loss are related with experiences, personality, values, views about life, the sense of threat, religious beliefs and cultural background.

**Aims:** Our aim is to show that the imminent death of these patients affects the medical and nursing staff during the provided quality of care and they experience grief when caring for terminally ill patients.

**Methods:** A systematic review was conducted in Greek and English literature (PUBMED, MEDLINE, PsycNET) from 2000 to 2014, about studies published or in development for the management of psychosocial and health care professionals' grief about the imminent death of the terminally ill. Based on inclusion criteria defined a priori, titles, abstracts and full texts were analysed to find relevant studies.

**Results:** Forty (40) articles met the inclusion criteria (Europe, USA, Asia). A common ground about all is that the imminent death of patients who are in the end-of-life affects healthcare professionals. There are differences between doctors' expressed grief compared to nurses, because of the different relationships that develop both specialties with patients and perceptions of their own about their role.

**Conclusion:** According to the findings of this review, death affects both medical and nursing staff. Therefore, it is necessary to run groups for psychological support of both specialties that work with the terminally ill patient. It is recommended to include education on death and care of the dying in the medical and nursing degree courses in order for healthcare professionals to be better able deal with issues that death evolves.

**Keywords:** Imminent death, dying patient, end-of-life, grief, bereavement, physician's & nurse's grief, perspectives, attitudes of healthcare professionals.

**Abstract number:** P2-167  
**Abstract type:** Poster

### Implementing a Telephone Bereavement Service in a Tertiary Cancer Centre

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**Background:** Bereavement is a natural response to the loss of a loved one. Some families may find this period of time extremely difficult, hence the importance of helping these individuals with supportive and caring bereavement services. In addition, NICE guidelines (2004) requires basic Level 1 support to be provided at all centres. Therefore a telephone bereavement service was implemented in the regional cancer centre in July 2013.

**Aim:** To evaluate the effectiveness and acceptance of the pilot telephone bereavement service at the centre.

**Method:** The audit looked at the number of acceptance forms returned from bereaved families over a period of six months, who were interested in having support. Background research was done in preparation for this study including contacting five large cancer centres on bereavement, observing the bereavement service at a local hospice and interviewing the founder of the new service at the centre.

**Results:** 82.6% accepted follow-up by this new service. The following benefits of the telephone bereavement service were found:

Information on bereavement provided with support available within 72 hours

Flexibility in the time frame regarding the follow-up telephone call

Families signposted to appropriate local specialist services

Bereavement staff have adequate training

However the need for certain improvements was highlighted. These included:

Providing contact details of already known healthcare staff to bereaved families to allow continuity of care

Sign-posting to other healthcare staff in the community eg. GP

Improving the education and knowledge of healthcare staff on bereavement in the centre

Additional information on the acceptance form

**Conclusion:** This study has demonstrated the benefit of the new telephone bereavement service. The next step is to compare data with the official hospital Bereavement Policy to ascertain if further improvements can be made to ensure high quality of care for bereaved families.



**Abstract number:** P2-168  
**Abstract type:** Poster

## Bereavement Support Groups in the Evangelical Lutheran Church in Denmark

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**Aims:** The project aims to

- 1) provide the relevant non-therapeutical bereavement care,
- 2) document and improve the quality of existing bereavement support groups in the ELCD, and
- 3) prepare the launch of more church-based groups nationwide.

**Background:** In *Recommendations for Palliative Care* (2011) Danish Health Authority focused on care for the bereaved and recommended that the National Health Care System, relevant organisations, and the ELCD identify and support people in need of bereavement care. In 2013 83 percent of all who died in Denmark were buried with the assistance of an ELCD minister. This indicates that bereaved people of more than 43.000 deaths were in contact with a minister at the time of their loss and farewell. Thus the ELCD holds great responsibility for people in need of bereavement care.

**Approach taken:** The project has explored and gathered data from support group leaders and participants via questionnaires and interviews, and has published the results in the report *Når sorgen bæres sammen (When Grief is Carried Together)*. The report describes both the positive experiences and the perceived challenges in working within this field. The findings have been integrated in a website for bereaved people and support group leaders ([www.sorggrupperifolketkirkens.dk](http://www.sorggrupperifolketkirkens.dk)), and in education programs for current and future group leaders.

**Result:** We have provided a framework for expanding the number of bereavement support groups (presently < 100 groups) and are working towards improving the quality of the groups.

**Conclusion:** Midway through the project period we can detect a rising number of bereavement support groups in the ELCD and a growing interest of participation from bereaved people.

**Abstract number:** P2-169  
**Abstract type:** Poster

## Little Touches – Huge Impact! Improvements in Hospital Bereavement Services focused on the needs of the Bereaved

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**Background:** In 2010 a joint Mortuary & Bereavement Service for the Trust was set up.

**Aims:** To develop a service, focused around the dignity of the deceased & the needs of the bereaved, whilst reviewing quality & turnaround time.

**Methods:** Existing facilities were upgraded & practices updated & developed in an area of vital importance, and the ELCD identify and support people in need of bereavement care.

**Results:** Provision of a professional uniform, staff education & development; rebuilding & modernisation of two entire mortuary & bereavement suites (include colour changing lights for skin effects); dignified, respectful transfer of patients in beds with a newly designed bed cover, rather than a concealment trolley & reduction in manual handling. Raising awareness for hospital staff helped understanding, reduced fear of the unknown, improved communication with families & adherence to care after death procedures. Updated procedures improved quality of death certification & professionally presented information in specially designed folders.

Many, apparently little, touches – quality ‘property bags’ for patients’ effects; ‘last thoughts, words & wishes’ cards; ‘forget me not’ seeded cards; keepsake pebbles; ribbon ties & muslin bags for hair locks; free parking for those collecting certificates have served to improve a difficult experience.

Redesigned, user-friendly bereavement booklets; staff cards with prompts for discussing tissue donation & departmental cultural awareness posters ensure cultural sensitivity to individual need; support for parents facing loss of a child & those who have miscarried, ensure burial & cremation facilities are appropriate.

**Conclusions:** Realtime feedback from the bereaved feeds further change. This presentation describes the difference that sensitivity & creativity have made to bereaved families’ experiences.

**Abstract number:** P2-170  
**Abstract type:** Poster

## Development of a Complicated Mourning Screening Protocol

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**Background:** Palliative Care (PC) stands for a holistic approach attending patient and family as a whole and extends care beyond death through bereavement support. To standardise attitudes and identify carers in risk for complicated grief we developed a Complicated Mourning Screening Protocol (CMSP).

**Aims:** To evaluate the CMSP accuracy in identifying carers in risk for complicated mourning, in a PC team.

**Methods:** Prospective analysis of CMSP records related to the patients deceased between November 2013 and August 2014

**Results:** 456 records were evaluated with 295 (65%) of deaths occurring in a hospital setting; 285 (62.5%) were males. According to the CMSP, 131 (29%) were elected for phone contact: 88 (67%) because of the carer; 35 (27%) for reasons related with the professionals; 8 (6%) for both. The main reason concerning the carers was the identification of risk factors for Complicated Mourning (75%), while by professionals was the need to closure the bereavement (60%).

Of the 131 carers designated to telephone contact, 49% weren’t contacted, 35% “didn’t need mourning counselling” and 16% were referred to the psychologist for mourning consultation. Ten of the 21 carers that received mourning counselling were already

discharged (median follow-up = 53 days and 2.5 appointments) and 3 (14%) presented risk factors for complicated grief.

Of the 325 carers (61%) designated not to contact (155 because of the scarce contact with the palliative care team), 7 (2%) asked for support but 6 were discharged for not displaying emotional distress related to the loss.

**Conclusion:** Although the vast majority of the carers (85%) had not been contacted by the PC team after the patient death, the CMSP permitted a rapid screening of the carers in risk for complicated grief.

**Abstract number:** P2-171  
**Abstract type:** Poster

## Population-based Bereavement Grief Data – For Policy and Practice Purposes

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A 2014 study sought bereavement grief information to determine if perceived death quality is associated with bereavement grief intensity. After a pilot study, six previously-used questions were added to an annual healthcare telephone survey of adult Albertans (a western Canadian province with 4.1 million citizens). Population-representative data were obtained from a weighed sample of 1208 subjects and analysed initially for descriptive, comparative, and correlational findings using the SPSS program. Findings: All but 5.4% had experienced bereavement grief one or more times, with most experiencing it many times (mean=8, median/mode=5); 75.9% were currently bereaved to some degree, with the most recent bereavement grief due most often to the death of a parent (21.8%), grandparent (17.9%), or friend (16.8%). Nearly half (45.9%) rated the death quality as more bad than good on a 10 point measurement scale. Bereavement levels varied, with 24.1% reporting no current grief and 18% reporting relatively severe current grief. Perceived death quality was associated with bereavement grief intensity ( $R=-.151$ ,  $p=.000$ ). Although more in-depth analysis is required, these initial findings reveal bereavement grief is a very common and impactful life experience. The bivariate association between perceived death quality and bereavement grief intensity suggests that the prevention of bad deaths is as important or possibly is more important for the survivors than the long-standing palliative care focus on the promotion of good deaths. More studies are needed to ensure that the expected increase in deaths due to population growth and aging does not greatly increase the burden of bereavement grief in society.

**Abstract number:** P2-172  
**Abstract type:** Poster

## Care after a Child's Death: The Perspective of a Pediatric Palliative Care (PPC) Team

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**Background:** Pediatric palliative care means being with a family in a very intimate situation, the process of dying. This is based on trust between patients, their families and the care professionals. Thus sometimes a close relationship develops between the family and members of the PPC team. With the child's death reimbursement for PPC by health insurances ends. However, some bereaved parents ask team-members to stay in contact or to be their grief counselor. Because contacts during bereavement depended solely on individual engagement of team members we decided to explore the requirements for a comprehensive aftercare program of both the families and the team members.

**Method:** We conducted a retrospective analysis of the charts of all consecutive patients of a specialised home PPC team to identify documented aspects of aftercare for bereaved families. Additionally team members were interviewed by a research team to get a deeper understanding of the care providers' needs.

**Results:** From 07/2009 to 12/2013 123 patients were treated by the PPC-team. During this period 65 patients died. In 49/65 (75%) cases further contacts with family/care giver after the child's death were documented. More than 50% of the documentations included home visits, other contacts were mostly by phone. Main content was the reflection of the course of dying, juridical questions, questions on bereavement, and openness for asking everything. In 4% the parents stated, that they did not want to stay in contact with the team. Main result of the interviews with team members was, that there is a need for a model of aftercare, that takes into account the individual needs of the parents. This model could support team members in their practice and should provide an individual way for care professionals to say farewell to the patient.

**Discussion:** There is a need for a structured model for aftercare in PPC that respects the individual needs of the families and allows a closure for all team members.



## Communication

**Abstract number:** P2-173

**Abstract type:** Poster

### Advance Directive in Terminally Ill Patients in Mexico: Family Vision

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The Advance Directive (AD) is a personal decision to undergo or not to media, medical treatments or procedures that seek to prolong life when you are terminally and for medical reasons, it is impossible to maintain naturally, protecting at all times dignity through signing the advance directive form (ADF).

**Objective:** To know the experience of families of cancer patients without cancer treatment and in palliative field to ADF. Telephone survey to 88 families of patients referred to palliative care services for terminally ill is performed. Questions included: AD and its fulfilment, AD format utility and ease decision making.

**Results:** 89% of the households surveyed reported having fulfilled the wishes and desires of the patient during the illness and after his death; 97% the ADF gave them a sense of security for the fulfilment of the desires and wishes of the patient and a minimum percentage were not accepted the AD patient because denial of his terminally ill patient despite the ADF. We conclude that the ADF facilitates decision-making and is a guide for meeting the needs and desires of the patient. The palliative care team should encourage the patient and family the ADF to establish their priorities and needs ensuring a good quality of death.

**Abstract number:** P2-174

**Abstract type:** Poster

### PACT: Development of an Intervention to Support Advanced Lung Cancer Patients and their Clinicians when Considering Systemic Anti-cancer Therapy; Phases I-II

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**Background:** Lung cancer patients approaching the end of life are known to receive systemic anti-cancer therapy, despite evidence that early palliative intervention can lead to less aggressive care and longer survival. The National Confidential Enquiry into Patient Outcome and Death recommended that treatment decisions should be made by the patient after they have been fully informed of the risks and benefits.

**Aim:** To identify the information and decision support needs of patients with advanced lung cancer, which will facilitate discussion of the risks/benefits of available treatment options.

**Methods:** This is a multiphase study. How treatment pathways are determined and presented to patients is explored via non-participant observation of up to six lung MDT meetings (Phase I) and 20-30 patient-clinician consultations (Phase II). These patients and clinicians will also be interviewed to explore perceptions of the treatment options and involvement in decision-making (Phase III). Extent of participation in decision-making is assessed using the OPTION tool. This data will be used to inform the development of an intervention to facilitate discussion about treatment options for advanced lung cancer; content development and acceptability will be undertaken via an expert consensus meeting (Phase IV) and cognitive interviews with patients (Phase V).

**Results-conclusion:** Phases I-II are underway, identifying patterns of patient allocation to treatment pathways. Data will be presented via the OPTION instrument's domains: identifying the problem; explaining equipoise; exploring expectations and concerns; checking understanding; eliciting preferred involvement. Any discrepancies between patients and clinicians in perceptions of the aim, risks or benefits of treatment will be analysed reflecting the domains of the observation phase. We hope that the resulting intervention will support both patients and clinicians in making informed and appropriate treatment decisions for advanced lung cancer.

**Abstract number:** P2-175

**Abstract type:** Poster

### Let's Talk about Sex. Doubts, Questions and Problems Relating to Sex Life Addressed to Doctors, Nurses, Psychologists and Physical Therapists by Palliative Care Patients

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The personnel who takes care of palliative care patients encounters a wide spectrum of problems. Being aware of the progressive illness that limits one's life causes that spiritual and religious spheres, as well as psychological support, become particularly crucial. However, discussions with palliative care personnel also pertain to more physical issues. Learning the patients' sex life-related doubts, questions and problems to be solved is also part of the palliative care.

**Aim:** Learning the questions about sex life most frequently asked by palliative care patients and their problems in this sphere addressed to the palliative care personnel.

**Methods:** A questionnaire directly addressed to doctors, nurses, psychologists and physical therapists working in palliative care in Poland.

**Results:** The questionnaire was responded by 54 hospice employees, including 26 doctors, 15 nurses, 8 psychologists, and 5 physical therapists. Most of the respondents (69%) were asked by their patients about patients sex problems during their professional practice. Most of them (52%) claimed that sex was discussed seldom or very seldom (22%). The discussion

was more frequently initiated by men than by women (39% vs. 15%) and it was more often conducted as part of the home care hospice. Only less than 3% of all palliative care employees said that sex questions were the permanent element of the interview. Discussions were initiated by middle-aged (48%), mature (19%) and young (19%) people. The main comment was grief over the loss of sex life, requests to improve their sex life pharmacologically and consent to sex life during the serious illness.  
**Conclusions:** The topic relating to sex life of the palliative care patients emerges in the professional practice of most of the palliative care professionals. Despite of the fact that this topic is discussed rarely, it is essential for people who begin to work in palliative care to be ready to discuss intimate issues.

**Abstract number:** P2-176

**Abstract type:** Poster

### Design to Enhance the Usability of Home Health Care Products and Improve Information Transfer to Reduce the Feeling of Insecurity for Patients and their Informal Caregivers

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**Introduction:** As the scene of health care shifts from the hospitals to home, people will have a greater responsibility to manage their health themselves. In such a change, they would need the right tools, information and access to help and assistance to manage/control their health effectively and with confidence.

**Aim:** This research aims to reduce the feeling of insecurity and vulnerability by trying to suffice the need for right information and care coordination and focuses to improve the usability of healthcare consumer products.

**Research method:** Based on the pilot study which was conducted through semi structured interviews and context mapping sessions with 33 Dutch elderly with chronic illnesses and their informal caregivers, it was realised that there lies a constant feeling of insecurity and vulnerability. It was also noted that the information transfer from the hospital to home is inefficient and unclear. Thus, this group needs help to shed the feeling insecurity and realise the responsibility to bring themselves back on their feet to reduce the burden on the healthcare system.

**Key concept:** A conceptual framework has to be designed to improve information transfer and care-coordination in a home care setting. It has been also noticed that using medical devices at home is not an enjoyable thing to do. People need immense motivation and encouragement to face numbers about their body. Hence, the interaction of consumers with such devices has to be drastically improved.

**Conclusion:** Improving information transfer, care coordination and enhancing the usability of home healthcare products can reduce the feeling of insecurity associated with patients and their informal caregivers.

**Abstract number:** P2-177

**Abstract type:** Poster

### Avoiding the Inevitable! Conversations with those thought likely to be dying and those important to them

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**Background:** The Neuberger Liverpool Care Pathway Review 2013, highlighted communication issues thought to account for major relative & carer unhappiness. The Leadership Alliance for Care of Dying People (LACDP) Response 2014 provided a focus to improve care of dying people & those important to them (family).

**Aim:** To establish whether conversations with dying patients & families met proposed recommendations of LACDP. Method: Notes of 100 random deaths Nov/Dec 2013 audited retrospectively against standards developed from LACDP recommendations. Data included conversation documentation, participants, content & timing.

**Results:** 13 excluded: 11 unexpected; 2 community deaths. 13 – no conversation documented: 10 no reason; 3 died before it could take place. 74 documented conversations: only two included patient; 59% same day as documented deterioration; 38% by registrar, 31% SHO, 13% consultant & 10% F1 doctors. In 47%, clinician documented that patient, or family, understood explanations. 41% included word 'dying' & 38% discussion of specific or uncertain prognosis. 38% documented presence or absence of patient's concerns, 83% discussion of plan for care; only 13% wishes of dying person.

**Discussion and recommendations:** Although most clinicians document conversations, not all important matters are covered, especially patient's wishes, understanding & explanation with clear use of the word 'dying'. Not all have conversations on day of deterioration, when staff should be proactive in contacting family & alerting senior team members. Within 24 hours, most senior clinician available should have & document a conversation with patient or family, including understanding, wishes & addressed concerns, to establish individual plan for care. The word 'dying' should be used, & an explanation of prognostic uncertainty with approximate time frame. All staff should see the patient's individual plan for care, in order to continue it & have background knowledge prior to further conversations.

**Abstract number:** P2-178  
**Abstract type:** Poster

## Developing Online Resources for Palliative Care – The Palliative Hub

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**Background:** Meeting the information needs of health and social care professionals and the general public regarding palliative care is important in a society where online resources are an increasing source of information. Providing this information digitally on one website location will reduce the burden on individuals trying to navigate the internet and multiple sources of information, which may not be appropriate or relevant.

**Methods:** Drawing on the skills and expertise of a range of stakeholders, a working group was established, which represented service providers, charities and advocacy groups. The purpose of this group was to assist with the design and develop the Palliative Hub, a website to provide information and guidance to health and social care professionals and the general public about palliative care. The website whilst providing information also acts to filter and direct the user to the most relevant sources of further information.

**Results:** It is anticipated that this resource will assist with meeting the information needs of health and social care professionals and the general public, in one place with key signposts to relevant information sources.

**Conclusion:** The Palliative Hub has the potential to become an integral element in meeting the palliative care information needs of health and social care professionals and the general public and is an example of an innovative and collaborative project across the island of Ireland, which could be translated across other jurisdictions.

**Abstract number:** P2-179  
**Abstract type:** Poster

## Building a Palliative Care Network: The Role of the Social Media in Cameroon

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**Introduction:** Open day celebration (ODC) is a key awareness-raising event for institutions to advertise their activities. The Bafoussam Regional Hospital (BRH) is the reference hospital in the West Region of Cameroon and it sees cancer patients referred for supportive care and a cohort of more than 4000 HIV patients. The new palliative care (PC) unit of this hospital is the only one in the region and is not yet known by the general population.

**Methods:** Free screening campaign for the most frequent cancer in our area was organised on the 2013 ODC of the BRH. Patients were sensitised on the prevention of these pathologies via radio interventions (looped for one week) of different specialists: a gynecologist, a surgeon and a palliative care specialist. Patients who responded via radio invitation were screened for cervix, breast and prostate cancer carried out by professionals. Local radios (4) and televisions (2) covered and broadcasted the 6 km city wide cancer and PC awareness walk organised in the morning of the ODC. Those who participated wore T-shirts and carried flyers with educative messages on cancer prevention and pain relief. A special educative workshop session on PC was organised in the evening of the ODC, for health care authorities and directors of the district hospitals of the region, as the first step to build a local PC network.

**Results:** 1103 persons participated during the screening for breast, cervix and prostate cancers while 255 subjects took part in the cancer and pain relief awareness walk. A register for patients with cancer was opened at the palliative care unit and most of them were referred for a first oncologist consultation before been referred back for supportive care.

**Conclusion:** Social media and ODC are powerful tools to advocate for PC and also to raise awareness in a given population on PC and its availability.

**Abstract number:** P2-180  
**Abstract type:** Poster

## Communication about Death and Dying – A Sociological Analysis of Institutionalized Palliative Care

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**Background:** Death and dying concern everyone, but literature and practical experience in a cantonal hospital in Switzerland show that communication about this issue is difficult and seem to have little importance in the clinical daily routine. However, communication about death and dying is seen as important to develop a social as well as clinical culture, but there is a gap between ideal and reality. By finding reasons for communication difficulties, explanations from an individual psychological perspective don't seem sufficient, they may be seen as topic of a larger sociological discourse.

**Aim:** This project shall help to understand the practical relevance of communication about death and dying and to capture interactive practice of communication in a cantonal hospital in Switzerland.

**Methods:** The project is designed as ethnography to explore the empirical field with various qualitative methods (triangulation). Grounded Theory is used for data collection and analysis. Qualitative interviews with palliative care professionals and associated stakeholders, participatory observations of palliative care consultations (including patients and if present relatives) and analyses of in-hospital concepts are conducted.

**Results:** 11 qualitative interviews with palliative care professionals and 3 with associated stakeholders have been conducted. One participatory observation of a consultation (whole consultation taped and transliterated with patient consent) and 8 reflections about palliative care consultations have been completed. Data collection is still going on considering Grounded Theory approach of theoretical sampling. A couple of codes have been found in the data material. Key categories and further questions have been elaborated.

**Conclusion/discussion:** In practice, addressing death and dying seems to be difficult for palliative care professionals. Acting in such specific situations makes high demands on them and high expectations often have to be scaled down.

**Abstract number:** P2-181  
**Abstract type:** Poster

## What Matters for Patients when Prognosis Is Uncertain? A Secondary Analysis of Qualitative Data

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**Background:** In our ageing population, an increasing number of people are living with complex advanced illness and an uncertain prognosis. Little is known about the effect of prognostic uncertainty on patient quality of life and patient priorities, or how patients cope with uncertain prognosis.

**Aim:** To understand patient experiences of living with an uncertain prognosis.

**Methods:** Qualitative secondary analysis of in-depth patient interviews; derived from 4 studies which investigated illness experience in patients with heart failure, chronic obstructive pulmonary disease (COPD), renal disease or cancer. Topic guides were assessed for comparability prior to analysis. We used purposive, maximum-variation sampling to select from the available transcripts, based on patients' age and sex, as well as content relevant to uncertain prognosis. We undertook thematic analysis of interviews. One researcher coded the data with 10% independent cross-checking to increase rigour.

**Results:** Of 98 available interviews, 30 were purposively selected. These included patients with heart failure (n=10), COPD (n=4), renal disease (n=10), and cancer (n=6). 40% were female; median age was 75 years (range 43–95). Major themes relating to illness experience were the importance of staying independent, loss of control over health, peer and family support, poor understanding of illness, and differences between patient and healthcare professional priorities. Key patient priorities were appropriate communication, quality rather than quantity of life, and dealing with co-morbidities unrelated to the primary diagnosis. We developed a typology for patients' responses to uncertain prognosis: contemplation of the future, practical planning, or disengaging.

**Conclusion:** Uncertain prognosis shapes illness experience for patients, and addressing patient priorities is important. We have developed a valuable typology of patient responses to uncertain prognosis to support this. This needs further testing.

**Abstract number:** P2-182  
**Abstract type:** Poster

## Finding the Words: Improving Conversations with Dying People & their Families

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**Background:** There is a clear need for precise & unambiguous communication which avoids the use of euphemisms when talking to people who are thought likely to be dying & their 'families'. The distress caused by poor communication was highlighted in the Neuberger Review 'More care, less pathway' 2013, a government review into care of dying people in England, & the need for good, clear communication outlined in the new Priorities for Care included in the LACDP 'One Chance to get it Right' response 2014.

**Aims:** To enable all clinical & non clinical staff, working in community, hospital & care homes in a well circumscribed area of the north of England, who encounter dying patients & their families, to feel they are able to talk about death & dying openly & confidently with those in their care.

**Method:** During 2013 we compiled a list of commonly used words & phrases which could be mis-constructed when talking to or about dying patients & constructed a list of useful alternatives.

These has been included in care of the dying training to more than 1600 individuals & printed on posters & business cards to be used as a handy reference in the workplace across care settings.

In addition "examples" of individual plans for care for those thought likely to be dying, have been circulated to clinical areas to support staff when documenting the conversations they are having.

**Results:** The language used by & between professionals is changing across our organisation as evidenced through communications with staff who constantly remind each other & this has been recognised at the highest levels of the organisation. Even non clinical staff are careful to use correct terminology at meetings. Audits of conversations documented show that clinical staff are documenting appropriate conversations.

**Conclusion:** Raising awareness of the importance of clear communication has also raised awareness of death & dying in the Trust.

**Abstract number:** P2-183

**Abstract type:** Poster

## Palliative Care in Patients who Are Not Aware of their Diagnosis

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**Aim:** To highlight the difficulties in communication with patients and family members when they are not aware of the diagnosis and prognosis.

To emphasise the importance of raising the awareness of family members on the patients' right of being informed on the diagnosis.

To emphasise the importance of the cooperation between medical staff and the patient and their family members when they are aware of the diagnosis.

**Methodology:** Data was collected from "Mary Potter" Palliative Care Center for the period January 2004 – September 2014. It includes:

-Information received from the patients' family members during the assessment of the referral and also during their training at "Mary Potter" PC Center.

-Information collected directly from patients.

**Results:** 1943 referral formularies are recorded for the period January 2004 – September 2014. 589 were cases of patients living in urban areas and 1354 in rural areas. 1790 patients were not aware of their diagnosis (462 urban; 1328 rural). In all cases family members were barriers to telling the patients the truth of their diagnosis. Family members reflected significant lack of information on palliative care and its purpose. The patients who were aware of their diagnosis and prognosis had established a quite effective cooperation with the palliative care team with regard to the treatment of their symptoms. The absence of a law on the communication of the diagnosis represents a barrier for the communication and collaboration between health professionals and patients.

**Conclusions:** Being aware of the diagnosis and prognosis by the patient is essential to achieving the purpose of treatment in palliative care. The education of patients' family members through trainings on palliative care facilitates the collaboration between the patients and care providers. Being aware of the diagnosis increases the reliability of the patient on the palliative care staff.

**Abstract number:** P2-184

**Abstract type:** Poster

## Palliative Care Patient Perceptions and Experiences of Medicines Information Communication in a Community Pharmacy: A Grounded Theory Approach

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**Background:** Poor symptom management and harm from inappropriate medicines use in the community is well documented. Misunderstanding medicines use is most commonly caused by poor communication, especially between patient and professional. Advice on safe medicines use is a community pharmacist (CP) role. High risk medicines e.g. analgesics are used in palliative care patients. Little is known of palliative care patients' communication experiences in a community pharmacy on using medicines safely.

**Aim:** To identify palliative care patient perspectives of communication barriers, facilitators and preferences for analgesic medicines information in community pharmacies.

**Methods:** A prospective study of face-to-face, recorded semi-structured interviews with a purposive sample of community based adult palliative care patients about experiences and preferences of obtaining information about medicines. The interview schedule, developed following literature review on barriers and facilitators to required medicines information exchange in community pharmacy, was peer-reviewed and piloted. Analysis of verbatim interview transcript data followed a grounded theory approach using constant comparison technique to identify factors involved in pharmacy based communication for palliative care patients.

**Results:** 11 participants. Communication with CPs about medicines was lacking. Adequate medicines information from contact with other health professionals was perceived by participants despite reporting needs around adverse impact of medicines on activities deemed important to patients. Lack of understanding of the CP role and reduced CP access as an unintended consequence of pharmacy medicines deliveries is revealed.

**Discussion:** Increasing pharmacist awareness about barriers to communication with palliative care patients may assist in improving access to medicines information support. The data indicate that CP communication appears to be only one influence on improved medicines understanding.

**Abstract number:** P2-185

**Abstract type:** Poster

## Implementation of Distinct Categories of Decision Criteria for Chemotherapy in Palliative Intention (CPI) in Clinical Care Processes

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Decisions regarding anticancer treatment in advanced, incurable cancer patients (pts) merit acknowledgment of multiple factors, beyond tumor-related and toxicity-grading risk-benefit judgments informed by oncology clinical trials. Early specialist palliative care (PC) studies suggest the potential of multidimensional and -professional approaches, but implementation of DC applied by oncologist in routine cancer care is challenging. To develop DC for CPI applicable in routine clinical cancer care.

Prior work (systematic literature review, interview guide, focus groups [4 FG, 15 pts; 2 FG, 17 physicians; 2 FG, 11 nurses], thematic qualitative data analysis, data reduction, Delphi consensus) retrieved 55 DC. 3 researchers independently characterised for each DC an appropriate group, then consensual defined them, the procedure was repeated until consensus.

Distinct groups include

1. preconditions (pt [7], physician [3], relationship [10], hcp staff/system [3], family [3]),
2. general information (cancer care [12], PC [5]) and
3. immediate interactive DC (12).

Pt-related preconditions encompass pts' illness / prognosis understanding, coping, meaning in life, relation to family, prior experience with cancer and anti-cancer treatments, pt-perceived trust and experience with specific oncologist and treating team. General information is pt and decision independent and may occur routinely, including pt information leaflets supported by nurse or physician information. Interactive criteria include among others pts-perceived clinical benefit, expectations, timing of assessing response, or impact of side effects on quality of life.

Implementing decision criteria in clinical care processes may require both preparation of preconditions, a background basic information and structured pt-physician interaction. Further research explores relative importance of retrieved criteria and groups.

Funding: Swiss Cancer League

**Abstract number:** P2-186

**Abstract type:** Poster

## Advanced Cancer Patients' Worries Related to End-of-Life and Perceived Communication with Health Care Professionals

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Advanced cancer patients (pts) face emotional and existential worries related to their approaching end of life (EoL). Addressing them is an essential palliative care (PC) intervention, but both pts may prefer to avoid thematising them and health care professionals (HCP) may collude with family.

To assess pts worries related to EoL, pts' self-perceived need to address them with a hcp, and the by pts' recalled addressing of those by a hcp.

The reported data is part of a larger observational study (268 adv cancer pts, defined PC needs, 74% ECOG 1+2), monthly collection of pt perceived needs/recalled delivery by hcp for 7 PC key interventions, demographics (adapted EAPC dataset), PC needs (IPOS), QoL (EQSD), and quality indicators (QI, inappropriate anticancer treatment, aggressive EoL care, quality of dying).

For the key intervention "EoL: preparation" patients were asked if they had 6 specific worries related to EoL (table 1), if they would have liked a hcp to address them, and if this had happened. The frequencies of the worries, need that the worry was addressed and recalled addressing by hcp is displayed in table 1.

Specific worry	% of patients that had this specific worry	% of patients with this worry that wanted this worry to be addressed by a hcp	% of patients with the wish that this worry was addressed where it was addressed
that the illness is spreading	62%	31%	65%
that I might have suffering that cannot be relieved	48%	32%	55%
that life time left is limited	40%	29%	52%
that the family is not prepared to cope with the situation	37%	30%	63%
that I won't be cared in the pace I would like	16%	42%	56%
that there is unresolved business concerning material aspects	13%	50%	59%

[Table 1]

78% pts needed spiritual issues (e.g. meaning in life, inner peace) to be addressed by hcp, but only in 42% it happened. Analysis of the influence of demographics, institutions, spirituality, illness understanding, symptom burden and proximity to death on these worries and evolution over time is ongoing. EoL worries are frequent in Romanian cancer pts who frequently prefer not to discuss with hcp, maybe also caused by the fact that the hcp were not appropriately available.

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**Abstract number:** P2-187  
**Abstract type:** Poster

## Clinical Management and Care Planning of Patients with Locked-in Syndrome in Palliative Care

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**Background:** The Locked-in syndrome (LIS) is characterised by tetraplegia, aphasia and preservation of the level of consciousness, and it's associated with a poor prognosis. The palliative approach to these patients is a challenge, given the fact that most of the patients were at the peak of the intellectual productivity and suffered great functional capacity losses and clinical problems, becoming prisoners of themselves.

**Aim:** To reflect on the production of care in palliative care for patients with LIS in Brazil.

**Methods:** This study combined: a integrative literature review with case study. Male patient, 29 years, married, photographer, with LIS after TBI, assisted at a hospice in São Paulo; detailed clinical and biographical history was collected with the family. Based on the data review a reflective discussion about palliative approach in LIS was conducted.

**Results and discussion:** In the literature, the care of these patients in palliative care is still a relatively unexplored field; in Brazil, there are no published studies. The identification of post traumatic LIS is difficult and is subject to misdiagnosis, which could be avoided through the association of serial clinical examination, imaging tests and multimodal neurophysiological evaluation. It was observed that the access issues to the health services can be worsening factors, as long as in the reported case it is assumed that the lack of early diagnosis and rehabilitation interfered negatively in the process, causing psychological and social suffering to the patient and his family. The care provided by the Palliative Care team could adequately provide emotional support to the patient and family, as well as symptom control, but integration with the Neurology and Rehabilitation was insipient. Further studies to assess a larger number of patients would bring a greater contribution to the management and planning of care for these patients, especially in palliative care, as well as integration among related areas.

**Abstract number:** P2-188  
**Abstract type:** Poster

## The Use of New Technologies and Social Networks to Spread the Philosophy of Palliative Cares

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**Background:** To report on what we do and how we do it is essential to our future patients with oncological and non-oncological advanced diseases and their families. The utilisation of new technologies and the proper use of social networks bring us closer to society and make our work easier.

**Aims:** We want to get the Palliative Care Unit of our hospital (with over 21 years of activity) has a separated section on the website of the hospital, intended to raise awareness of the work done, expand the healthcare services and include palliative care within the portfolio of an Acute Care Hospital.

**Methods:** We created a dynamic graphic design, with appropriate texts, with general and specific information about the unit and the team. Entryways, necessary procedures and videos of our facilities were included. We opened a communication channel in real time in Facebook, Twitter, etc...

**Results:** Data obtained were extrapolated after the publication on the web, 35 days go, of two articles on current palliative cares. We added, between visits, shared news and comments, an average of 121 daily records. By means of this tool we find a greater social sensitivity, improving of the experience of our patients at the hospital, and we could have also their opinion as a parameter for improved care.

**Conclusions:** To introduce ourselves as a group of interdisciplinary work, consultant, that provides continuous and coordinated care in different disciplines, helps the patient and his family to decide beforehand where and by whom he wants to be treated.

**Abstract number:** P2-189  
**Abstract type:** Poster

## Use of Interpreters in Palliative Care – A Practical Four Step Approach

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**Background:** Singapore is a multicultural city where numerous dialects are spoken. Communication in palliative care is difficult without a common language. Most healthcare professionals need to engage interpreters during some stage of their consultation. Many interpreters are not associated with health care and are employed solely for their language skills.

**Objectives:** To identify strategies for effective communication when using interpreters in palliative care consultations.

**Method:** Observation and reflective practice was used to identify strategies used to facilitate effective communication when using interpreters. Strategies were validated through discussion with professionals, including interpreters, from a variety of cultural and linguistic backgrounds.

**Results:** 4 steps: Basics, Exercise, Family conference and Debrief, contributed to effective communication. Basics ensure appropriate appearance and presentation of the interpreter. In the Exercise the interpreter translates a paragraph of information, with an emotive component. Although the health care provider is unaware of the accuracy of the information translated, this step provides the opportunity to look at facial expression, empathy, tone and duration of the translation. The interpreter can then be asked to modify their approach if necessary. The interpreter is then informed of the information to be translated and given the opportunity to express their emotional response and comfort level with the task. The Family Conference then takes place followed by a Debrief when the interpreter is able to reflect on the consultation.

**Conclusion:** This four-step approach is simple and easy to replicate with interpreters

irrespective of their previous experience and training. The approach appears to improve communication, providing more control of the interpretation and maximises the available interpreter resource, particularly when interpreters are given a short Exercise in translation before the Family Conference.

**Abstract number:** P2-190  
**Abstract type:** Poster

## Communicate for a Mutual Understanding: A Study on Training Needs for Palliative Care Professionals

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**Background:** Good communication between patients, caregivers and healthcare teams has assumed great significance in cancer palliative care. Literature shows that effective training may improve physician communication skills but the aspects of communication on which these training should focus has not been extensively researched.

**Aims:** This study aimed to determinate communication difficulties experienced by a group of palliative care professionals and to define their main communication needs.

**Methods:** Palliative care professionals' perception of difficulties in communication was assessed using a 22 item questionnaire containing two subscales: communication with the patient and communication with the caregiver. For both subscales has been calculated a cut off to discriminate between professionals' high and low perception of difficulty. Data analysis was performed with nonparametric tests and the Pearson test. P values < 0,05 was considered significant.

**Results:** One hundred forty-six palliative care professionals (81 physicians and 65 nurses) completed the questionnaire. Almost 65% of healthcare professionals experienced low perception of difficulties in communication both with patients and caregivers. The items recognised as the most difficult by the remaining 35% of the sample were:

- 1) understanding if the patient/caregiver has caught the information given
- 2) communication to the patient/caregiver of the treatment goals
- 3) understanding what and how much information the patient/caregiver want to receive.

**Conclusion:** The results of the current study indicated that palliative care professionals have difficulties in communication, both with cancer patients and caregivers, particularly in understanding the most appropriate way of communication in respect of everyone's specific needs and values. Patient-centered care requires professionals to be formally trained in a set of communication skills enabling them to effectively deliver a real tailored palliative care.

## Development and organisation of services

**Abstract number:** P2-191  
**Abstract type:** Poster

## Biggest Palliative Care Center in the Middle East, Kuwait is Competing with Time

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The state of Kuwait is an Arab country in western Asia. As of 2013 Kuwait has population of 3.719 million and 1.185 of those people is Kuwaitis.

With the yearly increase of the number of people, the incidence of the life threatening chronic diseases like cancer increased and the need for palliative care rises with time. Palliative care center (PCC) in Kuwait is the first stand center in the Middle East where patient care is integrated by a multidisciplinary team which aims at improving the quality of life for patients and their families.

The center was opened on May 2011, before this there wasn't any palliative care unit in Kuwait.

The PCC consists of 92 beds in total; it started with 2 wards with a capacity of 14 beds for 2 years then became 4 wards with 28 beds capacity in the third year.

In the first year 45 patients admitted, 4 patients were seen in the outpatient clinic. The statistical numbers are dramatically increased from year to year. All patients were treated by a multidisciplinary team free of charge.

Cancer type distribution among admitted patients to PCC was as follow: lung cancer 13.7%, head and neck cancer 12.33 %, colon cancer 10.05% followed by many other type of cancer. In this paper we will present the details of the profile of a palliative care patient in Kuwait, the feedback and the future plan for palliative care in the region.



**Abstract number:** P2-192  
**Abstract type:** Poster

## Kuwait Palliative Care Experience: A Small Country with a Successful Model in the Region Dr Iman Al Dirri

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**Background:** Many pain and palliative care initiatives are rapidly expanding around the world. Middle east is one of the regions where different models of such programs have been established over the last decade. Kuwait was one of the countries which realised early the importance of integrating palliative service into cancer care programs by establishing the first cancer pain clinic in the country in 1989.

**Method:** Different models of adult and pediatric pain and palliative care programs have been established over the last decade in the country. Services include an outpatient pain and palliative care service, a pain and palliative consultation team for hospitalised cancer patients, a pediatric palliative home care service, a pediatric hospice, and recently a palliative care hospital.

**Results:** By using different models of care our aim to build a promising palliative care service was successfully achieved. Breaking multiple barriers at medical and institutional levels was essential to achieve such a progress. Our opioid consumption was significantly increased over the last decade. In the WHO report in 2010 Kuwait was leading the east middle east and gulf region in opioid consumption. Using pain and symptoms assessment tools, educational programs for medical professionals, implementing WHO and EAPC cancer pain guidelines, cooperating with leading centers in the world were some of the methods we used to achieve such a goal.

**Conclusion:** Kuwait managed to break different barriers and provide successful models of pain and palliative care by adapting the services which respond to patient's needs and match the culture values. Kuwait model may help many countries in the region to develop their own program.

**Abstract number:** P2-193  
**Abstract type:** Poster

## Collaborative Care – How Can it Be Accomplished?

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**Background, aims and goals:** The Centre for Collaborative Palliative Care in Sweden started 2013, located at a midsize university. The overall aim of the Centre is that patients will experience good palliative care and family members will experience support before and after the time of death. This requires a solid palliative care developed in collaboration with patients, family members, health care professionals, and researcher. The aim of the presentation is to describe the activity of the Centre.

**Design, method, and approach:** The Centre is led by two researchers and a strategic board consisting of leaders from the university, representatives from the county council and communities, patients, and family members. The Centre has an operative group of 16 researchers and clinicians. A collaborative group with patients and family members participate in planning the work in the Centre. National and international networks within palliative care are also established.

**Results and conclusion:** The Centre has three main foci; education, clinical improvement and research. At the university, the Centre makes palliative care more visible in the nursing program and in courses at all levels. The improvement of the clinical practice is performed through offering education in palliative care to healthcare professionals and to implement good palliative care using a collaborative integrative learning process including families, health care professionals and researchers. Finally, the Centre conducts research projects to illuminate the meaning of a life with dignity when facing death from a patient, family member, family, and healthcare professional perspective and to develop and implement interventions to promote a life with dignity and dignified care.

With this unique Centre in which improvements of patients' and families' involvement and influence in the care are central, a well-functioning, sustainable care for all people can be realised.

**Funding:** The Kamprad Family Foundation.

**Abstract number:** P2-194  
**Abstract type:** Poster

## Organisation and Evaluation of General Palliative Care in Hospital – A Case Study

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**Background:** Hospitals have a responsibility to ensure that palliative care is provided to inpatients with illnesses they are expected to die from. Since 50% of the population dies in the hospitals, palliative care should be acknowledged and organised equally to other tasks provided by the hospitals. However, little is known about the hospitals' focus on, organisation of, and evaluation of palliative care.

**Aim:** The aim of this study was to investigate the organisation and evaluation of general palliative care at a Danish regional hospital.

**Methods:** The study was a retrospective case study using a large regional hospital as case. The case hospital had three different data sets, which all, in different ways, evaluated the standard and guideline for general palliative care. The data were 1. a national survey, 2. an external accreditation and 3. an internal self-evaluation. To investigate the organisation and evaluation of palliative care the data were triangulated in order to identify similarities and discrepancies.

**Results:** When the datasets were compared, the organisation and evaluation of general palliative care, provided by the hospital, did not seem to function in accordance with the nationally recommended approach, neither on the level of the hospital or the departments.

Many discrepancies were seen when comparing the datasets. 24 of 56 departments showed discrepancies on the knowledge and use of palliative guideline.

**Conclusions:** The results indicate that general palliative care is organised locally within the various departments and appears to function without an overall structure and position. When comparing the three datasets it is apparent that the triangulation is useful for identifying discrepancies in both the organisation and evaluation of the care. However, other methods might be more appropriate to investigate the nature of these discrepancies.

**Abstract number:** P2-195  
**Abstract type:** Poster

## R&D for Knowledge-exchange and Collaboration

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In 2002 several networks formed in North-East Skåne, Sweden, in certain priority areas with a view to increasing knowledge exchange and learning over organisational boundaries, with focus on the needs of the individual patient. The networks have developed into forums where hospital care, primary care, municipal care, specialised palliative care and higher education meet. They also promote a professional attitude irrespective of the type of care and are supervised by a management team who not only exercise control but also offer support. The Network for Palliative Care is one of ten networks with participants from above mentioned caregivers.

The aim of the Palliative Care Network is to increase and spread knowledge about palliative care so that the individual patient receives the best possible care irrespective of where the care is given.

Over the years participants have received continual in-service training via lectures, literature studies and individually designated courses. Mutual educational material has been compiled. National guidelines and recommended evidence based methods, for example, rating scales are continuously implemented. Mutual routines for as needed medication in end of life care and for information given on the transition to end of life care have been drawn up and a summarised version has been sent to all relevant caregivers.

The body of knowledge acquired through the years has led the participants to act as palliative representatives outwardly and as a key resource within their own units. The network participants convey knowledge primarily to those caregivers who are closest to the patient. The educational material and the written routines are frequently used. Statistics from the Swedish National Register for palliative medicine are used in the evaluation of results. The six municipalities and two hospitals together have a coverage ratio of 68–82% in the National Register. The result for individual questions is measured at the level of the individual unit.

**Abstract number:** P2-196  
**Abstract type:** Poster

## Dedicated Palliative Care Nursing in Denmark

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**Background:** We meet people in need of palliative care throughout the health care system and palliative care goes across specialties and sectors.

Danish Association of Nurses in Palliative Care (FSP) was founded in 2006. FSP is a sub-group under Danish Nurses Organisation (DSR) and all active members of DSR can join the FSP. FSP has 300 members.

FSP wants to develop the interdisciplinary palliative care at the basic level (home care and hospital departments) and on the specialised level (hospice and specialised palliative teams).

**Aims:**

- To gather all nurses in palliative care
- To disseminate evidence-based knowledge and visibility of nursing
- To create uniform palliative skills at all levels
- To be an active player in debate and to be involved in decisions about palliative care

**Method:**

FSP has nine members of the board representing different geography and specialties. FSP is active in national and European palliative groups and in public debate.

**Result:** Membership of European Association for Palliative Care (EAPC): FSP is the second European nursing association as a member of EAPC.

FSP want to promote a candidate for the Board and is represented by two members of the EAPC organising.

Membership of DMCG-pal: FSP is represented in the DMCG-PAL board and has been very active in the making of several national clinical guidelines and educational programs. Membership of Dansk Sygeplejeselskab (DASYS): FSP are asked for involvement in national issues that affect palliative care nursing. FSP organises annual 2-day courses and theme seminars with high professional quality.

**Conclusion:**

FSP has moved from being an association focusing on the establishment to focusing on participation in national and international work at a high professional level. FSP will stick to its core mission: To strengthen nursing in palliative care and to participate in the debate about education and values in the field of palliative care.

**Abstract number:** P2-197  
**Abstract type:** Poster

### Timing of Admissions to Specialist Palliative Care Units – A Service Evaluation

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**Aim:** A service evaluation of admissions to 3 specialist palliative care units (SPCU) assessing time of arrival & factors influencing arrival time.

**Methods:** A prospective review of all admissions to 3 SPCUs was performed during August/September 2013 & August 2014. On arrival to the ward, patient demographics, time of arrival, reason for admission, source of admission, notice of bed availability, mode of transport & performance status were recorded. Data were analysed using Microsoft Excel. 'Late arrivals' were defined as those arriving after 4pm based on a guide arrival time in units A&B.

**Results:** Data were collected for 148 admissions. 51% were male. 64% arrived before 2pm, 9% arrived after 4pm. 54% of late arrivals were delayed due to short notice of bed availability, all of whom were offered a bed on day of admission. 31% were delayed awaiting ambulance transfer, 75% of whom were transferred from a hospital. There were significantly more late arrivals in unit C than units A&B.

	Categories	A (n=72)	B (n=26)	C (n=50)
Time of arrival	<2pm	75%	66%	48%
	2–4pm	21%	31%	34%
	>4pm	4%	4%	18%
Source of referral	Homecare	42%	46%	38%
	Daycare/OPD	16%	12%	8%
	Hospital	42%	43%	54%
Type of admission	Symptom control	39%	38%	68%
	End of life care	43%	46%	32%
	Respite/Other	18%	15%	0
Bed offered	Day of admission	55%	27%	52%
	Previous day	45%	73%	48%
Mode of transport	Car	43%	38%	50%
	Taxi	14%	0	14%
	Ambulance	44%	62%	34%

[Results]

**Discussion:** Admission to a SPCU can be a time of distress for patients & their families. Patients who arrive 'after hours' will not be seen by the full multidisciplinary team & given a thorough holistic assessment until the following day. Recommendations to improve quality of care include implementing a guide arrival time for admissions, prioritisation of ambulance services for those being transferred to hospice, and giving patients advance notice of admission.

**Conclusion:** By implementing cost neutral recommendations, a higher proportion of patients could be admitted during core working hours. This will result in improved care for the patient and cost saving for the SPCU in reducing out of hours payments.

**Abstract number:** P2-198  
**Abstract type:** Poster

### Stakeholder Involvement in Health Technology Assessment Scope Development: Contrasting Views of Patients and Professionals about Issues Affecting the Organization and Development of Palliative Care Services

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**Background:** The INTEGRATE-HTA project is developing new methods to assess complex health technologies and applying these in a palliative care case study. Stakeholder involvement in Health Technology Assessment (HTA) is widely advocated to help ensure that results are useful to the end users. However, professionals, commissioners, patients and carers will have different concerns.

**Aims:** To identify stakeholder views of the key issues impacting on palliative care to assist with the HTA project scope development. This abstract focuses on the findings from England.

**Design:** 'Patient' (n=20) and professional (n=34) stakeholders were engaged as 'research partners' in individual or group meetings lasting 45–105 minutes. An adapted version of the EUnetHTA core model which guides HTA reporting and a scope diagram assisted face-to-face or telephone discussions. Thematic analysis identified key issues.

**Results:** Participants identified similar issues affecting the organisation and development of services. These included concern about public awareness of palliative care; the availability and accessibility of palliative care to various minority groups, staff education, training, support for carers and knowledge of the safety and harms of palliative care. Professionals queried what effectiveness in palliative care means whilst lay advisors wanted to know which elements of palliative care were effective. Professionals reported that improvements were needed to identify people with palliative care needs and co-ordinate services.

**Conclusions:** Having experienced the intended and unintended consequences of palliative care services, all stakeholders assisted patient-centred scope development by identifying important topics for HTA. Their early involvement will ensure that findings are useful to patients, families, carers, professionals and service commissioners.

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**Abstract number:** P2-199  
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### Outpatient Palliative and Hospice Care for Immigrants in Munich (Germany) – Integrating Multi-professional Service Providers

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**Background:** For immigrant populations, access to palliative care may be limited by communication deficits, lack of trans-cultural literacy, and individual preferences. In the Munich area, hospices, social welfare authorities, and health care providers have covered distinct aspects of palliative care issues so far. Here, an informal process of integrating these approaches is described.

**Methods:** During a first phase (2010–11), the nursing and psychosocial support team of Hospice Care DaSein was trained to provide end of life consultations for patients, families, and health care professionals with a focus on cultural and religious diversity. Main topics were symptom control, advance directives, and bereavement issues. Volunteers complemented the team. In a second phase of the project (2012–13), this core group then established a network with religious communities, municipal authorities, hospital discharge managers, general practitioners fluent in different languages, geriatric clinics, nursing homes, and funeral services. Moreover, working groups on immigration topics were actively contacted. Educational and public activities completed the program.

**Results:** Between 2010 and 2013, 688 patients were seen by the hospice team; among those, 111 (16%) had a migration background. The portion of patients from that sub-group rose from initially 9 (6%) in 2010 to 44 (23%) in 2013 which is close to their proportion within the entire population. Most patients were referred by hospital discharge managers, but sustainable support by their own communities was variable. In 2013, the program was regularly funded by public authorities.

**Conclusion:** Making hospice and palliative care services more accessible for immigrant populations in a municipal area is feasible. A next step towards a more sustained service implementation will be to explore specific needs and preferences regarding palliative and end-of-life care in this sub-group using qualitative interviews.

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### Direct Access from Hospital to Hospice Cutting the Red Tape at End of Life When it Matters!

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With patient choice being the guiding factor and with just one chance to get it right, the provision of good end of life care is a necessity. However, many patients and their carers find themselves in acute hospitals at this time whether on acute units or in busy A and E's. Hospices generally do not admit out of hours and have a referral process which can sometimes delay admission.

In a new initiative, a charitable local hospice is working with a large acute trust to cut the red tape and transfer imminently dying patients into hospice beds within hours. This not only reduces hospital deaths but increases access to hospice care. The rapid access beds can be admitted into directly by the Hospital Palliative Care Consultant, who upon assessment can phone the hospice at any time to transfer the patient and does not require a medic to accept the patient within the hospice setting. The Consultant completes a succinct medical clerking, drug chart and DNAR form within the hospital and then transfers the patient immediately. On admission to the hospice the emphasis is placed on nursing care and maintaining dignity, good end of life care and family support. The patient will be seen the next day by a medical professional for review.

This initiative has had a positive effect on patients and families; even when the patient has died within hours of admission to the hospice the family have felt this to be a good death, due to the excellent nursing care and the quieter, calmer environment. Effective and compassionate communication with family members is key at this time to ensure understanding of prognosis and the ethos of hospice care.

The hospital and hospice continue to work together to ensure excellent palliative care services for all patients within the local area, through identifying new ways of working together to increase and improve access to services and ensuring that patients have a choice in where they die.

**Abstract number:** P2-201

**Abstract type:** Poster

## Developing Home Based Palliative Care Service for Incurable Patients in the Capital of Moldova: Are There Any Limits?

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**Introduction:** Palliative care is a new field that was successfully implemented in many countries of the world, but in some states it still remains neglected by the national healthcare systems. In Moldova palliative care has been growing gradually since 2000.

**Objectives:** To assess the activity of the Charity Foundation for Public Health 'Angelus-Moldova' in regards of the provided home-based services for incurable patients. **Methods:** Review of the annual reports of the Charity Foundation for Public Health 'Angelus-Moldova' about its activity for different categories of incurable patients.

**Results:** Charity Foundation for Public Health 'Angelus-Moldova' is a leading provider of domiciliary palliative care services for incurable patients in the capital of the country. It was started in November 2001 with the mobile palliative care service for incurable cancer and non-cancer adult patients. In November 2008 the home based pediatric palliative care service for incurable cancer children was initiated, and later, in October 2011 the domiciliary palliative care service for incurable non-cancer children was launched. In December 2013 the home-based palliative care service for incurable HIV/AIDS patients was established. There are also two additional palliative care services at home: for women, who underwent surgical interventions due to the breast cancer and ostomy patients, when they become incurable.

**Conclusions:** Despite the fact that the National Program in Palliative Care is in draft, the Charity Foundation for Public Health 'Angelus-Moldova' still remains the only provider of qualitative domiciliary palliative care services for different categories of incurable patients in the country.

**Abstract number:** P2-202

**Abstract type:** Poster

## Delivering a New Model of Care to Support Residents in Nursing Homes

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Care homes are playing an important role in the care of older people at the end of life. Together, they provide final care for 19.6% of the population, rising to 30% of those aged over 85. Each year an average of 41,969 people die in a nursing home and 32,138 in a residential care home (National End of Life Care Intelligence Network, 2010). This poster describes an innovative model of care provision for improving EOLC in nursing homes through a case study which highlights its successful implementation in the Nursing homes within a local community. The service reports monthly against Key Performance Indicators which include visits to nursing homes for clinical and educational support, visits to General Practitioner End of Life Care meetings and support for development of individualised care plans on Coordinate My Care. Figure 1 Illustrates the model of education and training delivered to care homes Figure 1. Model of Education and Training for Care Home. The education was set at foundation level to include Health Care Assistants (HCA), and carers to participate alongside the Registered Nurses (RN). Clinical Nurse Specialists (CNS) also developed a 'clinical round' with nursing home staff. This was to identify those residents who were becoming more frail and showing signs of deterioration which may have indicated they were approaching the terminal phase. They provided role modelling and experiential learning at the bedside which helped to embed the theoretical educational sessions. Regular attendance at Gold Standard Framework (GSF) meetings with the GP practices attached to the homes enabled multidisciplinary working amongst professionals in the community! In Conclusion this poster reflects an innovative integrated model of care for nursing homes in a local community to support staff in being able to recognise residents who are dying. It is underpinned by theoretical knowledge and clinical role modelling.

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**Abstract type:** Poster

## What Happens to People on the Delayed Discharge List of a Specialist Palliative Care Unit (SPCU)?

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**Background:** Delayed discharges (DD) from hospital have detrimental effects upon patients. Delayed discharge from SPCU can prevent people being in their preferred place of care or prevent equitable use of beds for other needy patients. If home discharge cannot be arranged, there is a drive to pursue discharge to care home.

**Aims:** There is very little published research on the prevalence of DD, or what happens to people who are delayed discharges from SPCU. This led us to audit our own experience.

**Methods:** This was a retrospective case note review. All delayed discharges from our SPCU during 2013 were found via the NHS delayed discharge system. All notes were requested and data were extracted.

**Results:** Of 391 admissions, 21 patients were on the DD list. Data were available on 14 patients. 8 patients on the DD list were transferred from the unit to another place of care, 6 died waiting. The mean number of days that patients were on the DD list was 21 (2 – 62). 35% of people (5/14) on the DD list lived alone and none were discharged back home. If the palliative performance scale reduced in the time between admission and being put on the DD list, there was a trend towards a reduced chance of successful discharge ( $p=0.108$  Mann Whitney U test).

**Discussion:** 57% of patients on the DD list were discharged from the unit. If performance status deteriorated, there was a trend towards lower successful discharge, although this did not reach statistical significance. If people live alone at home, a supported discharge home is difficult to arrange. The delay in discharging someone to care home is about 1 month – making this an important practical consideration for our team and the patients and families we care for.

**Conclusion:** As a team, we shall take these data on board and consider whether it is in patient's and family's best interests to begin a process of discharge to care home from the SPCU for people with an objective reduction in PPS since admission.

**Abstract number:** P2-204

**Abstract type:** Poster

## Neurological Palliative Care – A One-stop-Shop Approach

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**Background:** The authors were aware that patients with non cancer diagnoses often need to access many different services and wanted to streamline their experience, whilst offering interventions that would be harder to obtain from other agencies, such as complementary and music therapy.

We incorporated a rehabilitative approach in order to offer practical solutions whilst using our specialist skills to facilitate excellent end of life care.

**Aims:** The aim was to introduce a model of care with a 'one stop shop' approach, which could be rolled out across a range of different disease groups, resulting in discrete, commissionable services. The model brings together professionals from a range of services to implement early interventions to maximise independence within the perimeters of the disease and avert crises.

**Method:** We implemented a multidisciplinary Motor Neurone Disease group which met fortnightly at the hospice and was open to both patients and families. We brought together the multi-disciplinary team from the acute and community sectors, hospice team, alternative and voluntary sectors to support patients and carers.

**Results:** The qualitative feedback is that the group has created a safe environment in which to have open discussions about all aspects of the progression of the disease.

It has resulted directly in integration of professional teams across organisational boundaries and increased partnership with other charities.

It has allowed us to test a model that we can develop across other disease groups.

**Conclusion:** Providing a one stop shop for people with MND has improved quality of life and increased choice and preparation leading up to death.

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**Abstract number:** P2-205

**Abstract type:** Poster

## Care Team, an Innovative Palliative Care Collaboration in Primary Care. An Evaluation Study

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**Background:** Dying on the preferred location is a quality indicator of palliative care (PC). In the Netherlands, most patients prefer to die at home. PC at home is provided by professionals and volunteers, from a variety of primary care organisations. Collaboration in PC at home is a challenge, due to a lack of regular face to face contacts. In a local area, primary care professionals and a high care hospice initiated the *Circle Team* (CT), a multidisciplinary collaboration of general and specialised PC caregivers to support patients and their families at home.

**Aim:** To support patients to die at their location of preference and ameliorate PC at home.

**Methods:** A prospective evaluation study.

Patients with a life expectancy < 12 months, identified with the 'surprise question' by PC professionals, were offered CT support. Patients supported by CT between Jan 2013–Dec 2013 enrolled in this study.

The CT collaborates through 2-weekly interdisciplinary consultation and 24/7 out of hours hospice consultation for patients, families and caregivers. All CT patients were registered in a database and a multidimensional patient record, to promote continuity of CT consultation.

**Outcome:** Concordance between preferred and actual place of death.

**Analysis:** Descriptive statistics.

**Results:** A total of 46 patients, 21 men (46%), mean age 72 (SD12.06), 93% cancer diagnosis, enrolled in CT for 97 days (SD96.8). In 24 interdisciplinary consultations, patients were discussed 5 times on average.

A total of 35 patients died: 83% (n=29) in concordance and 4% (n=2) not in concordance with their preference. The preference of 4 patients was unknown (inability to discuss death (n=1) and too ill (n=3)). These patients died at home (n=2), in hospice (n=1) and in hospital (n=1, saddle embolism).

**Conclusion:** Interdisciplinary collaboration and consultation in a local chain of PC generalist and specialised professionals and volunteers, supports patients at home, to die at their preferred location.

**Funding:** Zonmw



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**Abstract type:** Poster

## Starting a Hospital-based Palliative Care Program in Sub-Saharan Francophone Semi Urban Setting

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**Objective:** To organise a palliative care program is crucial for the effective follow-up and control of pain in HIV and cancer patients. The aim of this project was to organise and implement a system of primary care for people living with chronic pains in a hospital devoid of palliative care.

**Methods:** A strong and structured advocacy was made to the administration of the Regional Hospital of Bafoussam. Without morphine, we started psychological and supportive care to patients suffering from cancer and excruciating pain in the different hospital services during a period of four months. The need for oral morphine was then made and presented to the administrative staff of the hospital through the presentation of the PC concept and its precepts. This was then reinforced by the presentation of the results of a cross-sectional study carried out on the need for palliative care in the hospital. The need was also addressed to the chief nurses in the different services who were trained on the detection of patients needing palliative care in their services.

**Results:** Two people were sent on internship to the PC unit of the Regional Hospital Bamenda on the use of morphine. Thereafter, a mobile unit of PC was created, in the hospital in July 2013. After one year following its creation, 57 patients were supported, 21 home visits were also recorded to reassess the needs, continue care and provide psychological support for those who left the hospital, 5 condolence visits and many phone calls.

**Conclusion:** Creation of a successful system of care for patients in need of PC in a hospital setting is possible through innovative collaboration and organised advocacy.

**Abstract number:** P2-207  
**Abstract type:** Poster

## How Should Care in the Last Days and Hours of Life Be Documented? Views of Healthcare Professionals in a Tertiary Cancer Centre

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**Background:** Following an onslaught of media criticism and the publication of the review 'More Care, Less Pathway', in July 2013, the Liverpool Care Pathway (LCP) was withdrawn from practice in July 2014. With no national replacement, it is the responsibility of individual institutions to develop new documentation and guidance for staff.

**Aims:** The purpose of this study was to ascertain the views of healthcare professionals prior to the development and implementation of a new end of life care document at a tertiary cancer centre.

**Method:** Two focus groups with a range of healthcare professionals from the cancer centre were held to explore key areas in relation to end of life care. This included education, training and the role of electronic documentation. A literature review then explored recommendations for best practice. Finally a questionnaire was developed, piloted and distributed to staff across the centre.

**Results:** The response rate was 29%. Of the respondents, 90% had used the LCP within the last 2 years and 77% felt it should not be discontinued. 97% of healthcare professionals felt that end of life documentation should be multi-professional, 75% stated they would favour a similar format to the LCP and 50% did not want the new documentation to be electronic at this stage. 61% of staff had not received any training within the last two years and 78% believed that end of life care training should be mandatory for all clinical staff.

**Conclusion:** Multi-professional documentation without an electronic format was the key request from clinical staff, although the majority felt that the LCP should not be replaced. Mandatory education and training in end of life care was seen as the main priority in order to develop skills and confidence amongst the workforce.

**Abstract number:** P2-208  
**Abstract type:** Poster

## A Provision of Palliative Care Information for Patient and Caregiver in National Language – Project »Butterfly«

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**Background:** Positive aspects of palliative care in our country are not well recognised among professionals and in general population. Up until now, there was almost no written information available for public (general population) in our national language about palliative care.

**Aims:** To prepare written information about palliative care for patients and their caregivers in our national language.

**Methods:** A multi-professional group involved in daily palliative care work have prepared a list of topics that could help patients and caregivers during palliative treatment. We have invited several professionals from different health institutions across the country to contribute their knowledge and experiences to the project.

**Results:** 42 professionals from 15 different health institutions (8 hospitals, several primary care providers and professors at medical school, Hospice) have been collaborating in the project. The majority of information provided had been written by physicians with several other professionals included: 12 nurses, 5 social workers, 2 psychologists, 2 spiritual providers, 1 physiotherapist. We have prepared 20 different topics that cover most common physical symptoms (pain, subcutaneous pump, dyspnea, nausea/vomiting, delirium, fatigue, loss of appetite, constipation), nursing support (patient hygiene, ulcer prevention, lymphedema, dry mouth), psychological problems (child/teenager close to palliative patient, self-care for caregivers, how to talk to a patient), social questions (home care, institutional help), spiritual support, last days of life.

**Conclusion:** All 20 flyers were printed and distributed to all health institutions as a part of the World palliative care and hospice day 2014. For this purpose a new web page was

designed [www.paliativnaoskrba.si](http://www.paliativnaoskrba.si) where all materials are published with some additional information. A project 'Butterfly' is one of the projects running under supervision of The European Palliative Care Academy.

**Abstract number:** P2-209  
**Abstract type:** Poster

## A Map of Active Palliative Care Providers in Slovenia

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**Background:** There are several palliative care providers all over our country, but majority are not well recognised among patients, their caregivers and also among professionals. Many of them are not aware that palliative teams are available in their region as well as they do not know how, when or where to reach them and what kind of support can be expected.

**Aims:** As a part of Project 'Butterfly', which was developed for palliative care promotion and recognition among potential users of palliative care our additional aim was to make a list of all active palliative care providers and information on where, when and how they can be reached.

**Methods:** We have collected information about active palliative care providers from Slovenian Palliative Medicine Society members, Slovenian pain society and Slovenian hospital web pages.

**Results:** We have recognised 8 palliative teams in hospitals across the country, one specialised only for ALS patient, one for cancer patients and one for paediatric population. All other provide help to any adult palliative care patients. There is one mobile palliative team, 14 outpatient clinics for pain control, 8 hospice home support teams and 1 hospice house. As part of Project 'Butterfly' all recognised teams are presented on a map, as part of a new webpage [www.paliativnaoskrba.si](http://www.paliativnaoskrba.si) where patients and caregivers can also find the contacts and description of services provided.

**Conclusion:** The information how to reach any palliative care provider is crucial in sense of getting proper help when a palliative care patient is in need. With a list of active palliative care provider published on a new web page [www.paliativnaoskrba.si](http://www.paliativnaoskrba.si) we have filled that gap.

A map of an active palliative care providers in Slovenia is a part of the project 'Butterfly', one of the projects running under supervision of The European Palliative Care Academy.

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## Non-Governmental Organization Expenditure to Support Palliative Care Cancer Patients in a Lower-income Setting

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**Background:** Non-governmental organisations (NGO) play an important role in the delivery of palliative care (PC) for advanced cancer patients and their families. This is especially true in lower-income countries, like Egypt, where resources are limited. For different reasons, it was necessary to collaborate with an NGO to meet the needs of some patients treated in an Egyptian palliative medicine unit.

**Aim:** The study describes the expenditure of an NGO to support PC cancer patients in a lower-income setting.

**Methods:** Retrospective review of the expenditure of an NGO to support patients treated in an Egyptian palliative medicine unit based in a cancer center. The study covered 9 months period from January to September 2014. Expenses were categorised into medical and non-medical.

**Results:** During the 9-month study period, 34 patients received support from the NGO. The majority (62.7%) of the expenses were for medical care and 37.3% were for non-medical reasons. The main bulk of medical care expenses (42.7% of total) was to buy opioid analgesics (transdermal fentanyl patches). Other medical expenses were for non-opioid analgesics (6.2%), other medications (9.1%), supplies (3.2%) and investigations (1.6%). The non-medical expenses covered mainly the costs of daily living needs, like food, house rental, and transportation. The non-medical expenses extended beyond the death of patients for burial arrangements and family support.

**Conclusion / Discussion:** In our limited resources setting, a major part of the NGO expenditure is exhausted to purchase relatively expensive opioids for cancer pain control. Unfortunately, this was the only option available due to the unavailability of less costly opioids and the restrictive regulations that limit access to them. There is an urgent need to improve the availability and accessibility of less costly opioids in Egypt. In lower-income settings, the costs of daily living needs of PC patients and their families should be taken into consideration.



**Abstract number:** P2-211

**Abstract type:** Poster

## On the Construction of Design Guidelines for the Architecture of Palliative Care Settings in Denmark

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**Background:** The physical and psychological effect of architecture on patients, relatives and staff is being studied all over the world. The results of these studies are applied to designs of hospices, hospitals and nursing homes in Denmark. However the focuses of the studies are of a great variety and they involve many different types of patients and settings. Studies involving palliative patients are limited and an overview is lacking.

**Aims:** The aim of this project is to ensure, that relevant knowledge regarding the staff, patients and relatives needs concerning the architecture in palliative care institutions is collected, communicated and in the end applied to the architecture of palliative care settings in Denmark.

**Methods:** Design guidelines are created on the basis of a literature review and qualitative studies of e.g. existing palliative care institutions. The review is grounded on evidence based knowledge about health care architecture and literature about the knowledge of architecture in palliative care settings.

**Results:** The design guidelines are sorted out in five themes;

- 1) privacy and social relations,
- 2) functionality,
- 3) light, sound, smell and air and temperature,
- 4) nature and
- 5) atmosphere.

Each principle consists of four parts; a review, specific opportunities for designing, an overview of how one principle affects the others and a catalog of architectural references related to palliative care and the specific guideline.

**Discussion:** The guidelines are constructed from the (limited) knowledge within this specific field. But which criterias should be considered when selecting the studies? To what extend can conclusions from studies involving different groups of patients be transferred to the architecture of palliative care settings? And how can experience based knowledge or expert statements fill in the gap of evidence based knowledge?

**Abstract number:** P2-212

**Abstract type:** Poster

## Improving Emergency Admissions in Palliative Cancer Pathways

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**Background:** Patients with advanced cancer are often admitted to hospital emergency departments.

**Aims or goal of the work:** The main objective is to ensure equitable and coherent services to palliative cancer patients, were patients and users experience high quality of services during emergency admission. Patients experience a long admission process in the emergency department, that the organisation, competence and quality of services are not satisfactory.

**Design, methods and approach taken:** Redesign method was used to analyse the emergency admission process in an acute department of a Norwegian hospital to hospitalisation in the oncologic department. Data was also collected through semi-structured interviews of patients assessing their opinion about the admission process, next to medical data from hospital records indicating the amount of patients, when they arrive (time / day), their age and diagnostic background.

**Results:** The following improvement areas were identified: Changing the responsible physician from intern to resident to secure competence level. Development of a direct form to palliative cancer patients, that contain latest discharge summaries, updated drug list, and their treatment plan, to facilitate the admission process with direct discharge to oncologic department. The time of receipt. Patient should only encounter a team once and tell their story only one time. Intervention for pain management; an updated drug list must be in the patient's electronic record, to ensure that patients receive their prescribed drugs at dosing time. Outcome measures are reduced pain-relief.

**Conclusion/lessons learned:** Emergency admissions may be experienced as stressful events for palliative patients and relatives. By improving simple procedures, redesign the current process and higher the level of expertise, we can improve the emergency admissions process for palliative cancer patients.

**Abstract number:** P2-213

**Abstract type:** Poster

## Physician's Perceptions about Palliative Care Specificities

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**Background:** In a region with 250 000 inhabitants there are no Palliative Care resources, despite the existence of a group of trained professionals and approved laws. According to literature, the barriers to Palliative Care organisation are lack of education of the physicians and of the knowing of the resources, not understanding the benefits of Palliative Care and team work not organised.

**Aims:** To analyse the hospital physicians and general practitioner's perceptions regarding the specificities of Palliative Care.

**Methods:** A questionnaire was sent to physicians from three hospitals and seventeen primary health care centers and the difficulties faced with end of life were evaluated, taking into account aspects of Palliative Medicine and its importance on training. The collected data were analysed with SPSS and both groups were compared.

**Results:** From the 308 physicians, 105 answered (34%) the questionnaire. There were 49 males, 44 females; 61 (58%) were from hospitals and 43 (41%) general practitioners; 45 (42.9%) had 51–60 years (median age 52). Only 21 (20%) attended any course on the matter previously.

At the attitude's field, physicians had more difficulties in the suspension of ventilation and in the referral to another teams. At the communication's field, most difficulties were in prognosis. Organised teams were recognised as fundamental.

**Discussion:** Both groups showed interest and ability in team working, and was notorious the perception of importance of all chapters of Palliative Care in their training. The study allowed the identification of the physician's needs and difficulties and subsequent studies may complement and extend these results in order to build future strategies in the region.

**Conclusion:** The author concludes that a network can be implemented with complementary teams, adapted to the geographical characteristics and supported on a comprehensive and structured training program to all physicians.

**Abstract number:** P2-214

**Abstract type:** Poster

## A Network Model for the Future? Experiences from a Network of Physio- and Occupational Therapists as Part of a Multiprofessional Competence Network in Palliative Care

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**Background:** Interdisciplinary teamwork contributes to a holistic approach in palliative care. Both physio- and occupational therapists are important members of the team. However, the competence and knowledge in palliative care varies in this group, and there is limited knowledge among other professionals about their contribution in palliative care.

**Aim:** Increasing competence and engagement in palliative care among physio- and occupational therapists. Creating a platform for collaboration between health services and professions.

**Method:** An organised network of physio- and occupational therapists from different health services was established in 2007. The network, together with an existing network of nurses, established a multiprofessional competence network in palliative care in 2010. This also allows for other professions and is founded in the Norwegian guidelines for palliative care.

The network groups have a common steering committee, are parts of a formal contract and have common strategy documents. The multiprofessional network arrange seminars annually, coordinates web information, newsletters, annual plans etc., and annual evaluations are conducted. The different networks are lead by separate executive groups who arrange seminars and have their own web information and competence plans.

**Results:** Experience from this network model and annual member evaluation indicates increased competence and engagement for palliative care among physio- and occupational therapists and a better collaboration between different services and professions as a result of the networking.

**Conclusion:** This increased competence, engagement and collaboration is likely to contribute to a higher quality of physio- and occupational therapy and should therefore contribute to better palliative care. This networking model has inspired other regions in Norway to start similar networks and may be a useful model also for other countries.

**Abstract number:** P2-215

**Abstract type:** Poster

## Building Bridges – Palliative Care Beyond Borders

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**Background:** Globalisation doesn't stop in patients who suffer from an end stage disease, such as cancer. The incessant reduction of travel costs inevitably rises the number of travellers. Therefore, palliative care professionals will have to deal with an increasing number of patients with advanced conditions travelling from overall the world. The different cultural background, characterised by foreign languages, various beliefs and expectations can complicate the therapeutic relationship. These barriers may be further challenged in the event of a desired repatriation for terminal care. The purpose of presenting this case report and its related literature review is to identify cultural, psychosocial, spiritual, financial and organisational aspects to facilitate international travel for patients with end stage diseases.

**Case report and literature review:** We report the case of a 47 years old Mongolian lady suffering from an end stage cervix carcinoma, who travelled to Switzerland, expecting to receive a curative treatment for her advanced neoplasia. The desire for immediate repatriation came up after several weeks of hospitalisation with the awareness about the absence of any potential cancer treatment. The overall issues which emerged during this successful repatriation have been the topic of our literature review. Cultural differences may be overcome through the involvement of cultural interpreters, who are able to discuss the patient's expectations and allow the team to understand the various beliefs and rituals in end-of-life care. From an organisational point of view, thoughtful planning is mandatory, involving both administrative and healthcare aspects, assessing the travel risks accurately.

**Conclusion:** There are many challenges in the repatriation of patients with an advanced illness, such as medical, cultural and organisational issues. These need to be addressed properly, in order to guarantee the best possible well-being to the travelling patients.

**Abstract number:** P2-216  
**Abstract type:** Poster

## **Patients in Palliative Care (PC) Reluctant to Benefit from Hospital Monitoring: What Type of Collaboration Can General Practitioners (GP) Expect?**

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Could a palliative care network make bridges?

**Objective:** offer collegial sharing to GPs.

**Methodology:** Analysis of 5 cases encountered by our PC network in 2014.

**Example:** Two years after a breast cancer lumpectomy Mrs M. was refusing any further treatment or investigations and was ready to sign a liability release to her GP. Her nurse seeking advice from our network about pain treatment because the patient seems embarrassed to call her GP.

**Result:** Problems experienced by the GP in the cases:

- A dilemma between a feeling of failure to meet someone's distress and the desire to respect the inherent dignity of patients who deserve the right to make their own choices at the end of their life, even if it is to refuse facing reality.

- The frustration of being refused well-being treatments

- Patient's arguments for refusal can be clear or ambiguous

The external position of the network allows standing back to make more appropriate decisions. The multidisciplinary dimension can widen the scope. The actions adopt an ethical approach and take into consideration the patients as well as the relatives and the GP and nursing staff.

**Conclusion:** How to provide collegial support to GPs in spite of geographical and time constraints?

The ethical approach is based on a hospital model in which actors share a workplace. The exchanges between peers are easier in a 'medical home' structure. But not everyone can benefit from such an organisation.

The PC networks may take part to collegial exchanges when the patient doesn't wish to be hospitalised. It might be interesting to carry out a survey among GPs to build an exchange scheme more adapted to their daily practice.

Supporting professional at home is essential as most patients wish to die at home. The increasing difficulties in admitting more and more patients to the hospital, together with crowded emergencies departments, is another incentive to develop proper home care.

**Abstract number:** P2-217  
**Abstract type:** Poster

## **When Sociocultural Habits Re-humanize Patient Care: The Experiment of a «Wine Bar» in a Palliative Care Unit**

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In palliative medical practice, the question of how to take care and improve the quality of remaining life time is essential, restoring to the patient its human dimension also! It is also because palliative care tries to preserve for the patient the simple habits of the life that «happy eating and drinking» is at the center of our concerns. To restore desire is a way of giving hope that tomorrow exists.

**Aims:** The first is to improve the quality of the end of the life of our patients and to respond to their desires, even when they are unfavored by lack of means, family disagreements or sociological isolation. The second aim is to help the caregivers each day and to motivate the medical team with another way of taking care.

**Methods:** Once the purchase of the wine cupboard made, the symbolism of wine and food in a palliative situation was carried out by the nursing team, assisted by a socio-anthropologist who had already initiated a qualitative study on this subject.

We established with a statistician a data base with a questionnaire on the impact of this way of care, concerning patient's sensitivity, as that of their family and near ones, and of the nursing team.

Cooking workshops were created at the same time, arousing the curiosity of «all». We can mention the work of another hospital center proposing the implementation of gastronomic workshops.

**Results:** It shows that patients really appreciate this opportunity to taste a good wine and team explain the satisfaction, along with the pleasure of pleasing one another, the implication of the accompanying persons who find a meaning to this special moment that is the support of a seriously sick close relative to be able to give pleasure.

**Conclusion:** All in all this new generation of palliative care allows for pleasure. Sensorial experience is not only made through wines and food. We use all the sensorial dimensions: music, relaxation, essential oils, etc...).

**Abstract number:** P2-218  
**Abstract type:** Poster

## **Telehospice for Nursing Home Residents: A Cost-effectiveness Review**

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**Background:** Telemedicine is expected to efficiently provide specialist care to nursing home residents. Hospice care is sparsely available in nursing homes, whose staff often lacks training. Telemedicine for palliative care, also known as telehospice, could be an efficient adjunct to regular care in nursing homes.

**Aim:** The aim was to review the cost-effectiveness and effectiveness rationales of combining the method – telemedicine, the setting – nursing homes, and the need – hospice care.

**Methods:** International and french databases (Medline, EBM Reviews, Cochrane, Web of Science, Scopus, Banque de données en santé publique, Cairn, Francis, Pascal, OpenGray, Google Scholar and Doc' CISMeF) were searched for cost-effectiveness evaluations of the whole model. Combinations of its components (telehospice, telemedicine in nursing homes, and hospice care in nursing homes) were also searched for efficiency and effectiveness analyses.

**Results:** No publication evaluated the cost-effectiveness of the whole model.

Some health systems have found telehospice efficient, but strong evaluations are missing. It was found acceptable, feasible, and effective in training staff and caring for patients.

No cost-effectiveness study was found regarding telemedicine in nursing homes. It was found feasible at low cost, and effective in reducing hospital costs. Cost reduction was shown for chronic wounds and dementia management, staff training, and out-of-hours services.

Hospice care in nursing homes was proved efficient in the United States health system only.

It was found effective in promoting advance care planning and preventing hospitalisations. Staff training is effective only if followed by continuing support.

**Conclusion:** The efficiency of telehospice in nursing homes is suggested by the combination of its components' efficacy and efficiency. A pilot project including a cost-effectiveness analysis should be performed before broader implementation.

**Abstract number:** P2-219  
**Abstract type:** Poster

## **What Factors Affect a Patient's or Carer's Decision to Attend a Hospice 'Drop in Day' Service and Having Attended what Factors Influence the Decision to Reattend**

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**Background:** This report describes a piece of exploratory interpretive research relating to the evaluation of a 'Hospice Drop in Day'.

**Aims:** To explore what factors affect a patient's or carer's decision to attend a 'Drop in Day' service and having attended what factors influence the decision to reattend.

**Methods:** A feedback form was created and made available to those attending. 17 anonymous responses were received and this qualitative data was analysed using a grounded theory approach (Glaser, B., & Strauss, S, 1967).

**Results:** The identified motivating themes were: need for general support & social networking with similarly affected people, support another person, to access specialist advice, empathy, friendliness and cheerfulness of staff, enjoyment of the day, craft and therapy opportunities. Specific and general anxieties were the main factors dissuading people from attending. These anxieties dissipated after the first attendance. The theory statement is: A 'fit for purpose' Hospice Drop in Day provides an enjoyable networking experience where practical help and opportunities for creative expression are provided in an atmosphere of professional compassionate support.

**Conclusion / Discussion:** There were a variety of motivating factors to attend but provision of facilitated networking opportunities was most important.

Careful recruitment and training of staff is required to allow the professional but

compassionate atmosphere in the 'Drop in Day' to be created.

Services provided by volunteers such as art and other therapies are just as highly valued as those provided by paid staff.

The cost effectiveness of the 'Drop in Day' model makes it very attractive for Hospices in coping with ever increasing demands for services while resources remain limited. This research suggests factors which would make a 'Drop in Day' successful and can be used for any Hospice in development of this service. One would expect other Hospices to be interested in this research.

**Abstract number:** P2-220  
**Abstract type:** Poster

## **Sustainable Hospice und Palliative Care Culture in Nursing Homes: Connecting Nursing Homes and Community**

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**Background:** A large number of nursing homes (NHs) in the region of Aachen, Germany, have performed a process of implementing palliative care. There is an increasing discourse in Germany how and to what extent NHs can be part of 'compassionate communities' (A. Kellehear).

**Aims:** The participatory research study aims at answering the questions: Has palliative care culture been implemented sustainably in the participating NHs? To what extent do the palliative care processes enable NHs to engage in community care? In addition, the research process itself should foster partnerships between the NHs and the community.

**Methods:** 10 nursing homes (NH) of 8 different providers volunteered to participate. A steering committee consisting of the NH managers identified relevant actors for palliative care culture within and outside each NH. Each NH nominated one or more interviewers, who carried out 39 qualitative problem-centered interviews and 5 focus groups representing 5 perspectives: Residents, relatives, community members, professional co-operation partners and NH staff. The analysis was performed by the research team.

**Results:** All interview partners described attitudes of staff, explicit 'artefacts' (E. Schein) and structural changes that are outcomes of a successfully implemented palliative care culture. Expansion into community care constitutes a major challenge both for NHs and for communities. It was disputed in the interviews that community care is the task of NHs.

**Conclusion / Discussion:** Palliative care culture has been implemented sustainably in the participating NHs. There is evidence that the participatory study itself contributed toward sustainability. NHs and communities are social systems that do not connect sufficiently. In order to encourage NHs to engage in community care and vice versa to encourage communities to engage with their nursing homes further incentives will be required.

**Abstract number:** P2-221

**Abstract type:** Poster

## My Home Support a Collaboration between Housing and Hospice Care

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**Pilot aim:** To explore how housing support workers (HSW) could support patients and carers as part of the hospice's Clinical Nurse Specialist (CNS) team. CNS capacity was being reduced by undertaking important albeit non-clinical activities. Additionally the service received ineligible referrals that were nonetheless judged to be at risk of crisis where an assessment could be beneficial. The housing sector partner seconded a HSW into the hospice's 'First Contact' triage team. HSWs have valuable experience in supporting vulnerable clients and have knowledge of statutory and voluntary sector services, the hospice provided training on awareness of end of life care. The HSW makes contact with the patient and arranges a home visit to undertake a holistic assessment. The HSW supports the patient and their carers to access support including equipment, home adaptations, social care, benefit entitlements, in addition to liaising with healthcare professionals to organise GP reviews or District Nursing support where required. Between November and the end of June 2014, the HSW has managed 31 cases. The following indicators were evaluated via thematic analysis of case studies and clinical records by the partner organisations independently:

Support people to remain at home for as long as possible at the end of life if it is their wish.	Analysis concluded that the service has a positive impact on this outcome.
Reduction in inappropriate use of clinical time	Analysis concluded that the service has in all likelihood had a positive impact on this outcome
Reduction in accidental falls/injuries	Analysis concluded that the service in all likelihood has a positive impact on this outcome
Improved quality of life	Analysis concluded that the service has had a positive impact on this outcome
Reduction in social isolation	Analysis concluded that the service has in all likelihood had a positive impact on this outcome.

Reduction in unplanned admissions/readmissions to hospital Detailed analysis of five specific cases where avoidance of admission was judged likely undertaken and accepted by commissioners. Concluded that the service has been important in avoiding admissions, reducing length of stay and supporting home death in each case.*[Results]*  
Other key areas of learning: HSW supporting an unmet need for this group of complex patients with persistent pain despite intensive specialist input. Palliative Care has had a tendency to work in relative isolation from other pain specialities and the development a local Complex Pain MDT has been important in generating a fully integrated service.

**Abstract number:** P2-222

**Abstract type:** Poster

## Reflection on the Development of a Complex Pain MDT Meeting within a Specialist Palliative Care Department

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**Background:** Pain is common in the setting of advanced malignant disease, for a small number of patients (10%) pain will be difficult to manage using the WHO analgesic ladder.<sup>1</sup> Local surveys demonstrated an unmet need for this group of complex patients with persistent pain despite intensive specialist input. Palliative Care has had a tendency to work in relative isolation from other pain specialities and the development a local Complex Pain MDT has been important in generating a fully integrated service.  
**Approach:** A Complex Pain MDT approach has been developed, involving Palliative Care Doctors, Clinical Nurse Specialists, Interventional Anaesthetists, Pharmacists, Occupational, Complementary and Physiotherapists. Patients meeting the referral criteria are discussed on a monthly basis in an open, reflective and educational forum to generate a management strategy utilising all members' expertise.  
**Results:** In the last 6 months 43 cases have been presented. Internal audit has demonstrated a number of positive outcomes. For example, a case series of patients undergoing interventional procedures e.g. intercostal blocks, with a focus on pain and quality of life measures; increased referrals for non-pharmacological pain control measures such as acupuncture. As well as newly established patterns of joint-working between specialities e.g. neuro-rehabilitation.  
**Conclusion:** The MDT approach has resulted in improved patient outcomes while also providing a regular opportunity for professional education and development. Along with these positive outcomes it has also highlighted a local deficit in psychosocial support which has informed ongoing service improvement. The authors feel that the evolution of this Complex Pain MDT has provided a greater array of treatment options that should allow us to better meet the needs of our patients and could be used as a template for future services.  
**References:** 1. <http://www.who.int/cancer/palliative/painladder/en/> Accessed 13.10.14

**Abstract number:** P2-223

**Abstract type:** Poster

## Developing Palliative Care Services in a Resource Limited Setting – It Is Possible!

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**Aim:** To foster palliative care services in two streets in Kibamba, Dar es Salaam Tanzania by forming palliative care teams within the community and identifying patients in need of palliative care services.  
**Design:** Conducted two days introductory training on palliative care. Participants were

selected from the community based on the known compassionate and caring attitude they have. Training was conducted in participant familiar language; Palliative care tool kit which is translated in Kiswahili was used and distributed to all participants. Home visiting was done to patients to cement classroom learning. The training used didactic lectures, role plays and sharing of lived experiences.

**Results:** The training was the genesis of palliative care services within the community.

Palliative care teams have been formed and patients in need of palliative care are identified and cared holistically. Awareness has been created within the community on the needs of patients. Linkage is done and palliative care meetings are done once a month.

**Conclusion:** Palliative care services can be developed in resource limited setting by using a very minimal funds and available community resources. Building the capacity of the community to take care of their people is the only sustainable public health approach which can effectively work in scaling up palliative care in the developing world where the demand of palliative care is huge.

**Abstract number:** P2-224

**Abstract type:** Poster

## The Integration of Municipal Emergency Medical Services to the End-of-Life Care at Home in Rural Areas

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**Aims:** To ensure that all people approaching death will receive good symptom management delivered into their homes regardless of where they live. This is challenging in the rural areas with long distances as there are no 24/7 district nursing care outside of city centres. If acute crisis could be resolved at home, unnecessary transfers of the fragile, dying patients to hospital could be prevented and the patient would be able to stay at home as per their wishes.

**Methods:** A local training program and protocols were developed to ensure and strengthen the paramedics' knowledge and vision of palliative and end-of-life care. Emergency protocols enable adequate symptom management also at home. To achieve this goal, all dying patients must have a written medical end-of-life-care plan available at home.

**Results:** The paramedics participated into multidisciplinary training course led by a palliative specialist doctor and nurse. This education included the most common palliative emergencies and their treatments, also not forgetting the holistic approach focusing on the patient and family. Protocols were developed to treat these end-of-life emergencies and to administer appropriate medication. The importance of a carefully written care plan was emphasised in meetings with the local doctors and district nurses. The doctor on-call is available 24/7 by phone and the patient can be transferred into their local hospital by ambulance if required.

**Conclusion:** As the number of people receiving end-of-life care at home is increasing, our health care system must be ready to offer medical services and support to these patients whenever and wherever needed. Emergency medical services are available 24/7 also in the rural areas and should be integrated to the palliative care system promoting especially the end-of-life care given at home. When the management of life limiting illness is well-planned and organised, it can also be humanly good and economically sustainable.

**Abstract number:** P2-225

**Abstract type:** Poster

## The PATCH Service – Merging Oncology and Non-oncology to Provide an Equal and Expert Paediatric out of Hours Service

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The PATCH service (Paediatric Patient Advice by Telephone for Care at Home, Hospice and Hospital) is a specialist paediatric palliative care telephone advice service operating 24 hours a day, 7 days a week. The service started in 2010 for oncology patients and delivered a successful service over the following 3 years. In 2013 the PATCH service was developed further to cover non-oncology patients. The Paediatric Palliative Care Consultant who works across both Primary Treatment Centre (PTC) and Hospice observed an inequitable service for the two patient groups. Following review of an audit that took place for the oncology out of hours service the external professional service user feedback highlighted that they 'wished' there was a PATCH service for all their symptomatic/end of life patients and not just the oncology patients.

Government documents 'Better Care Better Lives' (DoH 2008) and 'NHS Commissioning Board' (2013) recommended that paediatric palliative care should provide a 24/7 on call service where possible for expert advice for children/young people their families and professionals involved in their care.

The PATCH team is funded and staffed equally between the PTC and the children's hospice. The on call offers a two tier system which allows for a prescriber and senior practitioner to be available on all shifts.

The PATCH team have weekly multidisciplinary team meetings and teaching to share knowledge and discuss medical and nursing management of the current caseload. The number of referrals has seen an increase since the non-oncology patient group has joined. There has been positive feedback from families via audit to aid continued positive development of the service, this audit trail will continue to collate data to demonstrate that the PATCH service is as highly regarded by the non-oncology patient group as it has been by the oncology patient group in the previous audit.



**Abstract number:** P2-226

**Abstract type:** Poster

## Developing a Strategy for Advance Care Planning: Choosing what Not to Do

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**Background:** Advance care planning (ACP) is the process of discussing and recording patient preferences around their choices for the future care and could potentially improve end of life care. despite increasing evidence regarding ACP, uncertainty remains on the best way to do this. The regional Network which is a virtual organisation comprising of commissioners, providers of specialist palliative care, general palliative care and end of life care services, patients and carers have appointed a clinical lead to guide this process.

**Aim:** To develop a comprehensive regional strategy for a system wide process to support community, hospital, hospice and long term condition providers develop a sensitive and responsive approach to ACP.

**Method:** A 12 month project is underway to identify strategies for developing ACP including: scoping best practice; clarifying definitions; and making recommendations on resources and educational models, using a top-down and bottom up approach.

**Results:** Preliminary findings are that key principles need to be embedded first into everyday practice with emphasis on patient choice. Results will be presented at conference.

**Conclusion:** Research suggests that understanding ACP process is key to implementation and that good practice can be embedded by recording and sharing conversations alone on standardised documentation. Training and public engagement are fundamental to promoting and maintaining change.

**Abstract number:** P2-227

**Abstract type:** Poster

## Bridging the Gap – How Research-ready Are Palliative Care Services in Sussex?

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**Background:** The Sussex Palliative Care Research Specialty Group (SPCRSG), a regional UK research group, was set up to promote palliative care (PC) research and increase recruitment in Sussex. However, the research needs and capabilities of organisations represented by the group were unknown.

**Aims:**

- 1) To identify factors that promote Sussex PC services to participate in research and barriers encountered
- 2) To understand research capabilities of services.

**Methods:** A postal survey was sent to the clinical leads of all Sussex PC services. The 14 services included 7 independent hospices, 5 NHS hospital PC teams and 2 stand alone community teams. Survey questions covered items related to service details, service research experience and capability, and barriers/factors promoting PC research. Collated results were analysed. Summary statistics used.

**Results:** The response rate was 100%. Within the 14 Sussex PC services, less than a quarter stated that they had been involved in PC research in the last year. Nearly 60% of services had research included in their business or strategic plans, but one third did not have a specific nominated research lead. Enthusiasm/motivation for potential research involvement was the most common factor cited to enable participation (7/14), as well as previous research experience (4/14). Time constraints were most commonly cited (10/14) as barriers to participation and lack of research experience (4/14). Access to a research nurse (6/14) and dedicated research time (4/14) were cited most commonly as helping services participate in future palliative care research.

**Conclusions:** There are unmet research needs for PC services across Sussex (regardless of whether services are voluntary sector or NHS services). These need to be addressed to ensure research participation. Future directions involve inter-regional collaboration between other interested research networks and development of a local research infrastructure to support successful delivery.

**Abstract number:** P2-228

**Abstract type:** Poster

## Development of Continuous and Complete Palliative Care in Zagreb Improved by the Multidisciplinary and Interdisciplinary Approach and Teamwork

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The aim of this study is to emphasise the improvement of palliative care development in Zagreb achieved by implementation of basic principles of palliative care. Multidisciplinary and interdisciplinary approach to palliative patients and their families as well and the service organisation contributed to the better quality of care and the growth of palliative care network.

Development of palliative care in Zagreb has started 20 years ago but only four years ago significant changes have started taking place. They were induced by the initiatives on all the levels of the society: general public, professionals, local and national authorities. In the City of Zagreb three teams have developed their domiciliary palliative care activities and mutual collaboration; a church-based charity as a non-governmental organisations (social worker and volunteers support patients and families), a project mobile team supported by the national health insurance (doctor and nurse provide symptom control) and a coordination centre for palliative care supported by the local government (palliative care nurse specialist plans care at home and coordinates palliative care teams and all the service providers and different health care levels). Even the teams are based in different organisational setting and

team members meet different needs they work together as one broad team providing care for the same patients. Through continuous meetings, joint education and supervision team members accomplish personal and professional growth as individuals and within the team. In such a way the help to patients facing life threatening illnesses and their families is not just the sum of services but complete and continuous care.

Despite the current growth palliative care development in Zagreb requires time and effort for more improvement and has a support of 'Strategic Plan for Development of Palliative Care in Croatia 2014–2016' issued by the Ministry of Health.

**Abstract number:** P2-229

**Abstract type:** Poster

## Developing a Primary Care Computer Record Search to Facilitate Identification of Patients with Palliative Care Needs

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**Background:** Most people in the United Kingdom spend much of their last year at life at home and could benefit from a palliative care approach during that period. However less than 30% of people with non-malignant disease are identified for such an approach before they die. The use of information technology currently in place in general practices provides an opportunity to systematically identify more people for a palliative care approach at an earlier stage than presently.

**Aim:** To develop a primary care electronic record search to identify patients with unmet palliative care needs.

**Methods:** A computer record search was developed and tested in fifteen general practices in two Scottish health boards. A sub-set of patients identified by the search were selected for further review and care planning by GPs. Quantitative and qualitative data were collected to assess the impact of the search results on practice behaviour and attitudes towards the search among professionals and patients.

**Results:** The electronic record search successfully identified between 0.6 and 1.5% candidate patients, some of whom the practice reviewed and identified for palliative care. Starting an Anticipatory Care Plan, and sharing it with Out of Hours services using a new national system which updates secondary care daily was the most common action GPs undertook for patient identified by the search.

**Conclusion:** Electronic searching of primary care records can identify a shortlist of patients to assess for palliative care needs. Regularly producing such lists at team meetings can increase the number of non-malignant patients with anticipatory care plans shared with secondary care. Computer searching for patients with advanced diseases in primary care and an electronic system for daily sharing of key information about such patients should be further explored.

**Abstract number:** P2-230

**Abstract type:** Poster

## Implementing a Dignity Care Intervention (DCI) for Individuals with Life-limiting Illness in a Community Setting in Ireland

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**Background:** Evidence indicates that people at end of life fear loss of dignity more than anything else. What defines dignity for the individual patient and his or her family is unique. A central tenet of palliative care is to help people die with dignity. Whilst there has been an increase in emphasis on care in the community, there is lack of guidance on palliative care for community healthcare professionals.

**Aim:** To implement a Dignity Care Intervention for individuals nearing the end of life in a community setting in Ireland.

**Methods:** The MRC Framework for Developing and Evaluating Complex Interventions was used for this multiphase mixed methods study.

Phase 1: Contextualising the DCI tool using focus group interviews with user/carer representatives (n=10) and community nurses (n=18). These explored the use and applicability of the tool for an Irish context.

Phase 2: Educational programme for community nurses (n=54);

Phase 3: Implementation and evaluation of DCI in practice: 4 pilot sites, across rural and urban areas are implementing the DCI tool in practice.

**Results:** Findings from Phase 1 identified issues such as reluctance to discuss 'feelings'; having a desire to please others' alongside issues of communication within the primary care context. Feedback from the educational sessions indicated an increase in confidence and competence for implementing the tool in practice. Realistic evaluation approach is ongoing including focus groups (n=4) and semi-structured interviews with patients and carers (n=20).

**Conclusion:** The complexity of implementing a tool in practice cannot be underestimated. Greater understanding of such issues will contribute to the future development of practice and subsequent improved care for patients approaching the end of life.



**Abstract number:** P2-231  
**Abstract type:** Poster

## Integrated Community Palliative Consulting Care Team the Active Care in Hungary

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**Background:** Cancer patients are seen in a variety of clinical settings. Many evidence describe that palliative care reduces the symptom problems, improve the quality of life. Some evidence describe that after the palliative consulting service the 51% of patient transferred to others hospice care. Our palliative care consult team is a group of dedicated health care professionals working together. Our services include both inpatient consultations and ambulatory care clinic visits.

**Goal:** We can help to the pain management and other physical and/or emotional symptoms, to facilitating community support, to facilitating decision-making and to navigating advanced care planning (home care, outpatient palliative care, inpatient palliative care). We aim to improve the quality of living and dying for patients and their families coping with challenging, advanced or life threatening illness.

**Methods:** The palliative consulting care team – such as pilot program – started 2 years ago in the University of Pecs Clinical Center. In the team have 2 physician, 1 psychologist and 1 palliative nurse coordinator. The palliative nurse coordinator specialist is available 8:00–16:00, five days each week, and during the weekends answers the advice line as well as being available for face-to-face consultations in the clinical profile of 28 different departments.

**Results:** The total number of palliative care consulting was 450 cases. We found, that after the consultation, the families preference the home care better and that reduce the number of hospital admissions. The poster describes the experience, and the use of task of consultative care.

**Conclusions:** That consultations with a palliative care team are beneficial and enhance the patient's discharge time increases.

**Supporter:** University of Pecs Clinical Center and Pecs–Baranya Hospice Foundation

**Abstract number:** P2-232  
**Abstract type:** Poster

## Improving Palliative Care in North Wales

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The Betsi Cadwaladr University Health Board (BCUHB) provides community palliative care to a population of nearly 700,000 people across an area of over 6,000 km<sup>2</sup> [1]. In seeking to address the existing challenges of providing effective community palliative care across a largely rural area, a greater use of informatics has been advocated. Existing specialist palliative care services are delivered by small teams with accredited training which support the complex needs of patients, families, carers and healthcare professionals. As part of the wider Welsh Assembly Government (WAG) strategy 'Developing Primary and Community Services' [2], we explored ways to improve efficiency in the delivery of this care. As well as improving the use of wireless technology through enhanced bandwidths at existing community hospitals, all community palliative care clinical staff were issued with the most suitable VPN-enabled hardware with an integrated video conferencing facility. Enhanced use of informatics sought to optimise utilisation of specialist knowledge and skills by increasing time for patient contact and medical education. These telehealth solutions standardised professional working practice by optimising clinical record keeping and data input as well as reducing travel times and costs. Consistent with the national programme 'Together for Health – Delivering End of Life Care' [3], more efficient team working enhanced the quality of care given to patients and their families during palliative treatment. This was captured by the current 'I Want Great Care' national survey.

This project was funded with £72,000 from the Welsh Assembly Government 'Health Technology and Telehealth Fund'.

[1] WAG 'Local Authority Population Projections (2006–present), Summary Report (2008)

[2] BCUHB: Health Technology and Telehealth Fund 'Developing Primary and Community Services – Project Initiation Document' (2013)

[3] WAG 'Together for Health – Delivering End of Life Care' (2013)

**Abstract number:** P2-233  
**Abstract type:** Poster

## Fundraising Initiatives for Palliative Care in Kenya: Building Support through Membership Schemes – A Case Study from KEHPCA

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**Background:** Kenya Hospices and Palliative Care Units (KEHPCA) is the overarching body that supports all aspects of Hospice and Palliative Care throughout Kenya. From its inception in 2007 it has supported the growth of palliative care from 14 providers to over 50 providers in the country, serving a population of over 40 million people. Like many other developing countries, Kenya is faced with an increasing number of patients faced with life limiting illnesses such as cancer, diabetes, HIV/AIDS, hypertension among others. Majority of these patients present late where cure is not possible and the only solution is palliation hence the growth in the number of patients across the country in need of palliative care services.

**Aim:** To address sustainability in palliative care.

**Methodology:** KEHPCA is a non-profit organisation and the grant funding it receives is extremely generous but this is restricted to specific programs of work such as training and advocacy leaving a need to raise unrestricted funds. Funds raised from unrestricted funds helps KEHPCA in purchasing morphine and other pain relieving medicine for patients with life limiting illnesses, develop IEC materials, support the day to day office running activities among other activities.

**Results:** The organisation raises unrestricted funds through annual membership

subscriptions for individuals and corporate, charity walks, educative movie screening and sale of branded merchandise such as T-shirts and wrist bands.

**Conclusion:** There is need for national associations across the borders to build up their membership schemes. By so doing, they will be able to raise extra funds which do not fall under the restricted funds and in turn support hospices and palliative care units in meeting the needs of the patients in their region.

**Abstract number:** P2-234  
**Abstract type:** Poster

## Preparing for the Future

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**Background:** Changing population demographics and the call to meet the needs of patients with a non-malignant diagnosis (currently 16% of all our hospice referrals) have led us to review our inpatient unit (IPU) service – a resource-intensive (and costly) part of our service. We have 10 beds for a population of 550000. This specialist service provides for a small proportion of the total hospice patients who might need admission for symptom control, acute respite, planned respite, rehabilitation, and/or terminal care. We ask what measure(s) exist to demonstrate efficient use of existing resources, and how do we use these to prepare for future demand?

**Aim:** To collect additional information regarding bed occupancy and to compare this with 'throughput', benchmark against other units, and look at the effect of changes in demand upon these measures.

Findings for 2013–14 (2011–12 for comparison): 270 admissions (222), 29% on the day of request. 12% non-cancer primary diagnosis (6%). 69% 65 years or older (60%) Average length of stay (LOS) 9.8 (10.4) days.

**Occupancy:** Clinical database: 74% (62%) Manual data: 72% at 24:00 hrs; 71% at 09:00; 73% at 17:00 – these figures mask considerable unpredictable fluctuations from day to day. Holding a bed for an admission accounted for an additional 10% of available bed days. An 11% increase in admissions or an increased LOS of 1.1 day would have increased our 'occupancy rate' by 8% to 80%. Throughput has increased to 27.3 (23.4). Comparative data will be reported.

**Conclusion:** Demand has increased. No national recommendations exist for ideal 'occupancy rates' or 'throughput' and definitions are inconsistent. Data is only comparable in the context of unit size (and LOS) as neither reflects the greater impact on small units of time of death and holding beds. 'Bed turnover interval' is worth further exploration. We need to be clear whether it is a 'full' IPU that makes for an efficient use or whether it is being able to provide a bed in a crisis?

**Abstract number:** P2-235  
**Abstract type:** Poster

## Introducing a 24/7 Home Care Palliative Service

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Cyprus has an estimate of 3000 new cancer incidences and about 1200 deaths from cancer each year. All palliative care services are pioneered and operated by the voluntary sector only.

The Cyprus Association of Cancer Patients and Friends (PASYKAF) is an NGO dedicated in improving and safeguarding the quality of life of cancer patients and their families. One of our main services is palliative care services at home. In 2013, our multidisciplinary team offered palliative care services at home to 1800 patients.

Our service currently runs from 7am to 6pm so we are implementing a 1 year pilot project in order to develop and provide a 24 hour service beyond our office hours. At the moment no other Association or entity offers this in Cyprus.

We aim to improve our offered health care services, improve the capacity or our nursing staff, transfer the existing knowledge from two partners in this project, the Norwegian Cancer Association and Turkish Cypriot Cancer Association and publicise our new service and make people to feel comfortable to have home treatment. Ideally, with the completion of the project we plan to set up the model for implementing this service across Cyprus.

The key objectives of the project are the following:

To introduce a pilot service of 24 hour service to patients of our organisation in 2 out of 5 districts in Cyprus (Nicosia and Limassol)

To improve health care services, while we reduce costs both for patients and our association through the evaluation of the pilot service

To improve the capacity or our nursing staff through training

To enhance our e-health database of our patients to web-based

To evaluate the project and examine the quantitative and qualitative impact of this service, including a financial viability report

To publicise our new service and make people to feel comfortable to have home treatment The project will be completed in May of 2015 and we will be able to present all results at the EAPC 2015 Congress.

**Abstract number:** P2-236  
**Abstract type:** Poster

## 'Plus Sport la Vie' Physical Activities (PA) Program for Patients with Cancer

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**Background:** Many studies indicate that physical activity (PA) can contribute to maintain physical function in patients with advanced and progressive disease, with a good impact in quality of life. Some physical and psychological symptoms can be improved (fatigue, sleep, mood, pain, peristaltism...). Improvement of survival length is shown in some study (High grade relapsing Glioma, + 7 months).  
**Aims:** Setting up an adapted PA program for patients with cancer during or after therapy: running, challenges, prospects.  
**Method:** Introduction to the design of the project, activity sessions report since March 2013.  
**Results:** 'Plus Sport la Vie' program is a tripartite agreement Marseille University Hospital-School of Medicine-'Ligue contre le Cancer'. It has been made for any patient regardless of the cancer treatment center, allowing an access to 3 adapted physical activities per week taught by cancer specialised trainers in adapted physical activity in the Faculty of Medicine' gymnasium and outside, in a natural park. Written and oral communications about this program have been performed. We created a sport and cancer association, resulting in a departmental broadcasting. It has funded a training 'sport and cancer' for a physical activity educator.  
**Discussion:** Although PA prescription is now recommended at diagnosis of cancer, it is not often done. Many barriers to this practice have been identified, especially in cancer advanced stages coming from PA proposal, organisation, patients and physicians. This non-drug therapy is based on the only will of the patient. Developing psychological support, dietary counseling and link with therapeutic education program in association with PA are under study, as well as the development of research project.  
**Conclusion:** Feedback from patients who participated in the program are very good, with improved fitness, reduced disease symptoms and treatment side effects as studies made us hoping. Sustaining the program remains a priority.

**Abstract number:** P2-237  
**Abstract type:** Poster

## Municipal Institutions that Provided Special Palliative Care Programmes in Denmark

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**Background:** Research has shown that the number of Danish municipal institutions that provided special palliative care programmes (MISPC) has increased during recent years. The aim was to map and examine the characteristics of MISPC in Denmark.  
**Method:** The research followed a mixed-method design combining quantitative questionnaires, mainly answered by directors of municipal health departments, directors of nursing homes and palliative nurses, with qualitative interviews with representatives from ten of the MISPC involved in the questionnaire part.  
**Results:** The research found that 40 institutions in 34 municipalities provided special palliative care programmes. Alone from 2012–2013 the number of the institutions increased by 43%. The establishment MISPC was based on a mixture of political, economic, geographical and professional grounds. Most of the institutions had between one to ten beds and mostly housed elderly people with life-threatening diseases. The palliative care provided had a holistic perspective with focus on everyday life; activities and rehabilitation, symptom management and end of life care. The professionals working with palliative care mostly included care-assistants, nurses, occupational therapists and physiotherapists. Only nine institutions had a physician attached and only one third of the institutions in the survey offered training in palliative care.  
**Conclusion:** The research showed a difference in the composition of professions in MISPC compared to specialised palliative institutions. MISPC's focus on everyday life and rehabilitation may be caused by employment of more groups of therapists and social and health care workers, which could affect MISPC's ability to provide palliative care and rehabilitation in everyday practice. Few nurses at MISPC may indicate that the institutions do not offer outpatient palliative care services. Just as only few physicians attached to the institutions could add to the pressure on general practice.

**Abstract number:** P2-238  
**Abstract type:** Poster

## From Pioneers to Recognition – Developing Palliative Care in Sweden

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**Background:** The general development of palliative care in Sweden during the last decades has been positive in terms of official recognition, professional development, availability of services and professional competency.  
**Aim:** To describe the development of PC in Sweden through the perspective of official and professional documents and activities.  
**Methods:** Activities, documents and different initiatives related to PC development were collected through members of the board of directors of the National Council for Palliative Care (NRPV) and through the archives of the Council.  
**Results:** The Swedish Society for Palliative Medicine (SPPM) was founded in 1997. A curriculum for education in Palliative Medicine, based on the UK and EAPC curricula, was published in 2001. NRPV was founded 2004 with economical support from the government, and consists of 11 professional PC national organisations. NRPV is responsible for the national PC conferences and publishes the Swedish palliative care periodical.

The Swedish register of Palliative Care was initiated in 2006 with the goal to collect data from all expected deaths in Sweden. Registry variables reflect quality indicators aiming at increasing quality of end-of-life-care. SPN – Swedish Palliative Care is the monthly electronic national newsletter reaches approx 4000 e-mailaddresses.  
A government recommendation 1995 listed patients in need for PC as the highest prioritised group for health care. Recommendations on PC were in 2001 published by the government and national directives for PC in 2013. Palliative medicine will become a medical subspecialty in 2015. All PC is integrated in the official funding of health care.  
**Conclusion:** There have been an increasing number of professional and official supportive activities, initiatives and documents in PC during the last decades. Next priority is education for professionals as well as equity of access to quality assured PC.

**Abstract number:** P2-239  
**Abstract type:** Poster

## Experiences and Needs of Relatives of Dying Patients in Switzerland: A Qualitative Narrative Study

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**Background:** In 2010 the Swiss health board approved a national strategy for palliative care. This first qualitative study in Switzerland about the experiences of family survivors after the death of a relative hospitalised in a palliative care ward.  
**Aim:** Presentment of the experiences and needs of relatives of dying patients. These experiences cover the time from diagnosis to hospital treatment, home care and a specific palliative ward, where the patients died at the end. Furthermore, we elaborate the meaning of the professional support for the family members.  
**Method:** retrospective interviews Twenty-one narrative interviews with bereaved relatives, conducted after the death of their beloved ones on a specialised palliative care ward, were performed using a semi structured interview guideline. The average time of the interviews was 75 minutes, they were digitally recorded. The transcripts were analysed using a qualitative content analysis. Data Saturation was obtained after 18 Interviews. The study was approved by an independent ethic commission. Results On the caring level, the relevancy of having a person, as a confidant, was shown as one of the main benefits for the family members. This fact escaped by the remembrance which a deep focus on aspects within the quality of life aspects, than on medical management for symptoms. This confidant helped to alleviate difficult situations by communicating, performing rituals and giving room for valediction.  
**Conclusion / Discussion:** Palliative Care ward offers a support resulting in a wide overall satisfaction. The practical and theoretical implications can be seen in the affirmation of the need of extending palliative care on interpersonal aspects. The Study clearly shows that quality of life, plays a major role in the course of dying. Multifaceted interpersonal phenomenon in dealing with the dying and their relatives are more important factors for the remembrance of quality of life than good symptom control.

**Abstract number:** P2-240  
**Abstract type:** Poster

## Innovations in the Transition Process Supporting Young Adults with Life-limiting Illness

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**Introduction:** Moving from children's to adult services can be a difficult transition for young adults and their families. We know that services are poorly coordinated, and this can lead to frustration. Service provision is also inequitable and in turn, lead to teenagers, young adults and their parents becoming socially isolated and disengaged.  
**Method and results:** During 2014, we set up a pilot project, funded by the DAISY Foundation. We identified over 40 young adults aged between 17 and 25 who lived in South East London and were being discharged from children's hospice services from community paediatric services. The project team consisted of a Young Adult's Coordinator (A Community Nurse Specialist) and an Arts Therapist (2 days a week). Healthcare Assistants and volunteers supported the work when needed and a steering group oversaw the project including representatives from Children's Hospices as well as other key representatives and a young adult user.  
1. We arranged joint home visits between the project lead together with other significant professionals from community services, created a co-ordinated care plan using a newly designed assessment tool. We explored Advance Care Planning and then entered everything onto a central register.  
2. We set up regular Young Adult Days, including siblings, friends and carers. We offered support with transport and we involved local schools who provided students who came along to befriended and support the Young Adults.  
**Conclusion:** This poster will outline the project and its success and will also include information regarding future developments, successful funding bids and potential roll out.

**Abstract number:** P2-241  
**Abstract withdrawn**

**Abstract number:** P2-242  
**Abstract type:** Poster

## Retrospective Review of Quality of Documentation in Patients Discharged 'Home to Die' from Hospital

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**Background:** Around half of all deaths in England occur in hospitals, even though many like to die in their own place of care. It is recognised that Health care professionals are required to respect patients wish to achieve preferred place of death. We aimed to document the baseline quality of discharge documentation of those patients discharged 'home to die' for end of Life Care.

**Objectives:** To check relevant pathways used effectively & patients who were discharged home for end of life care given appropriate medications, healthcare professionals are communicated to coordinate the support the patient/carer likely to need.

**Methodology:** Retrospective case notes review of 30 patients who were discharged home for end of Life Care at Home. Patients were identified using referrals to Crisis Support Team(Hospice).The following items were checked: Home to Die check list, discharge decision(from medical notes entry), GP/District nurse informed,palliative care form completion,crisis medications prescribed,documentation of patient discharged home to die (for end of life care) in EDN, DNACPR for completed and communicated to GP, DNACPR sent with the patient.

**Results:** 27/30 had poor completion of Home to Die check list.29/30 had poor completion of palliative care handover form.18/30 discharged within 48 hours of decision to discharge.9/30 patients had GP informed, 20/30 had District Nurses informed.14/30 had evidence of medications review,29/30 had crisis medications prescribed.Only 5/30 patients had clear documentation of 'Discharged Home to Die' in their discharge letter,23/30 had DNACPR form completed and communicated to relevant professionals.10/30 patients had their DNACPR forms inappropriately left in their notes.

**Conclusion:** We found overall need for improvement in documentation and communication to community health care professionals(GPs,District nurses and Palliative care team). We plan to update the discharge the check list, EDN and educate the teams to improve the situation.

**Abstract number:** P2-243  
**Abstract type:** Poster

## The Impact on Care for Cancer Patients of a Cancer Support Team in a University Hospital in Japan

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**Aims:** To evaluate the effects of a cancer support team in a university hospital.

**Methods:** We established a multidisciplinary cancer support team (palliative care physician, psychiatrist, nurse, pharmacist, medical social worker and physiotherapist) in April 2008. We analysed all cancer patients referred to the team during a period from 2008 to 2013.

**Results:** In the past 6 years ,2421 cancer patients were referred to the team. Approximately 40% of the patients were under treatment of chemotherapy and/or radiotherapy. The annual number of patients increased gradually. The median period of intervention was 17 days. The reasons for the referrals were pain (39%), anxiety/depression (31.5%), insomnia (27%), delirium (5.9%), edema (3.7%),fatigue (2.2%), and nausea/vomiting (1.5%). The others were family support, drug administration guidance, and discharge support.

**Discussion:** The total number of referral is more than tripled in comparison with the average number of referral in other university hospitals in Japan. This may be due to not only a naming of the team but also well recognition of the team in our hospital. The next challenge is to enhance both the quantity and the quality of the team activity and provide high-quality care to patients with illnesses that are not limited to cancer.

**Abstract number:** P2-244  
**Abstract type:** Poster

## The Possibility to End Life at Home – A Measure of Good Palliative Health Care?

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Every individual has the right to be involved in the design of their well-being. Many critically ill patients state a desire to end their lives in their own homes. Both the patient and their families must experience that the situation is secure in order for a patient to be able to end their lives in their own homes. If not, hospital care or other in-patient care are the only options available. ASIH-healthcare providers in Stockholm have a long common mission for advanced home care. This means that one can compare the operations (14 pcs) from different perspectives.The percentage of enrolled who die at home in relation to the total number of deaths in the home or in direct connection to ASIH-healthcare varied in 2009 from 18%–64% between the various healthcare providers.The possibility for patients to have health care in the home at the end of their lives depends on many factors, such as family members' willingness and energy to care for the patient at home, access to healthcare providers (ASIH) and physical ability to adapt the home for the patients needs. It also requires that healthcare providers prioritise the well-being of patients and their families in terms of feeling secure and well-cared for. This also involves offering fast access to healthcare providers both day and night. Perhaps the most important factor is the team's (nurse, doctor, physiotherapists)

expertise and ability to prevent unwanted outcomes by detecting the patient's need for support and care initiatives in time.If the above requirements are met, conditions are created to give the patient and their families security in the situation.

**Discussions:** Is high proportion of deceased patients in the home an indicator of good ASIH-care, which implies that the patient and family feel secure, showing strength in the palliative situation?

What is an appropriate target for the proportion of ASIH patients who die at home?

**Abstract number:** P2-245  
**Abstract type:** Poster

## Basel Needs a Hospice – Let's Build One

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In Switzerland there are exclusively private health insurance companies that have the right and the power to consent to or reject the coverage of a hospice admission. They also decide about the length of stay they are going to pay for and what portion of the costs will be covered. If they do consent, the medical request must be renewed and submitted every 6 week. Based on this request, the health insurance decides whether to continue or to withdraw the financing of the stay.

A day in a hospice costs ca. CHF 1000/day in Switzerland. If the initial or the prolongation request is turned down, the patient and her/his family are faced with huge expenditures, or she/he has to be admitted either to a hospital or to homecare. This system puts immense strain on already severely burdened people. Furthermore, the administrative expenditure is considerable.

These circumstances prompted a group of four health care professionals in Basel (Switzerland) to design a hospice with a different funding system. The plan is to have a hospice (with and without walls) with a foundation that covers the deficit costs from patients who can't pay the whole stay. It takes ca. CHF 50'000 to found a foundation. To come up with this amount of money the group decided to found a charitable association, 'Verein Lichtblick Hospiz Basel' with the aim to collect the money necessary for the creation of the foundation. The association is operational since December 2013. One member of the group was lucky to get admitted to the new course 'Leadership and Management in Palliative Care' of the European Palliative Care Academy funded by the Robert Bosch Stiftung. The inputs from this training provide the group substantial and valuable support regarding 'how to plan and run a project'.

**Abstract number:** P2-246  
**Abstract type:** Poster

## Integration of Palliative Care Program (Home Care) and Oncology Palliative Program in Advanced Cancer Patients: Clinical Benefit and Quality of Life

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**Background:** In the last decades, longer survivals and new treatment side effects in oncology enforce a novel strategy of early comprehensive cancer care including palliative care and anticancer therapy to better meet patients' needs.

**Aim:** We report preliminary data of a prospective observational study of Palliative Simultaneous Care, conducted by the Palliative Care Unit of Hospice Villa Speranza in Rome and Medical Oncology Unit of Policlinico A. Gemelli between January 2013 and August 2013, in order to confirm the improvement of QOL with a concurrent approach.

**Methods:** We considered 21 patients (9 males and 12 females), median age 63 years (35–84), KPS < 50 in 9 patients and ≥ 50 in 12 patients, PaP Score 0–5.5 in 16 patients and 5.6–11 in 5 patients, affected by advanced solid tumors or hematological malignancies. During our observation all patients received palliative care in home setting and cancer therapies as outpatients.

**Results:** At the time of statistic evaluation, 13 patients were dead but only 1 of them in hospital. The symptom burden was assessed through the Edmonton Symptom Assessment Scale: our evaluation at 1 week (n=19) and 1 month (n=13) registered a positive variation of ESAS score of 4.88% (p=0.34) and 2,24% (p=0.64) respectively. A statistical significance after 1 month was reached for loss of appetite (1.74%, p=0.02).

**Conclusions:** Our data suggest the effectiveness in terms of QOL of a model of concurrent palliative care. An efficient palliative simultaneous care program offers also a realistic chance to choose the place of death, as demonstrated by the low rate of deaths in hospital, that represents also a better way to allocate resources.



**Abstract number:** P2-247

**Abstract type:** Poster

## Service Redesign: Development of a 24/7 Triage Service

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24 hour seven day a week telephone advice has been provided by the hospice for several years. Calls outside traditional normal working hours were dealt with by nursing staff working within the in-patient unit of the hospice and were reported to cause a significant distraction from face to face patient contact. Patient and relative feedback indicated a wish to have a single point of contact for advice.

In response to feedback, a decision was taken to implement a dedicated advice and telephone support service for patients, relatives and health and social care workers. Several models of service delivery exist within the United Kingdom, usually led by nurses operating at an advanced practice level. No extra funding was available for a service development. The nursing establishment was reconfigured to enable the commencement of a 24/7 Triage Service. The service is staffed by Registered Nurses at a registered practitioner level. In the first month of the service, without any formal publicity to the local community, 594 calls were handled and 124 patients were supported by the service. This represents a significant reconfiguration of activity. Initial feedback across the hospice service indicates a positive response with staff being freed up to concentrate on their patient care. Patients have offered feedback demonstrating a positive experience of their contact with the service. The nursing staff providing the service have found the experience positive and anticipate on-going professional development of skills in communicating and caring through telephone contact. The service has been implemented with minimal additional cost and utilising a lower grade of nurse than that commonly used in similar services and demonstrated the effective use of the hospice communication infrastructure including the electronic patient record. Formal evaluation will be undertaken at six months.

**Abstract number:** P2-248

**Abstract type:** Poster

## Rehabilitation for People Living with Cancer

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**Background:** A growing body of evidence shows that many patients with advanced cancer disease have unmet PC needs at an early stage of their disease trajectory, and several studies indicate that these patients benefit from a PC intervention. It seems logical, that a PC intervention aiming at patients in earlier phases should be tailored differently than for end phase patients, and contain elements of rehabilitation. We developed and established an out-patient service: 'Rehabilitation for people living with cancer' which opened in January 2014 at a national cancer centre.

**Aim:** Our overall aim is to improve patients perception of health and quality of life.

**Methods:** We based the development of the service on

Studies of symptoms and needs in the population

Reviewing relevant literature

reviewing clinical guidelines

Studying best clinical practice

Our own expertise and experience as a specialist palliative care team

During the first year we continuously evaluated the service with patients, and implemented changes according to their feedback

**Referral criteria:** Advanced cancer disease, complex symptomatology and suitable performance status. Patients were seen by doctor and nurse and screened with EORTC-QLQ-C30 before and after the 12-weeks intervention, and presented at our multi professional team meeting. Possible interventions: Physical exercise in small groups, Educational programmes in groups for patients and relatives addressing physical symptoms, social, existential, and psychological issues. Dietary advice, individual consultations by psychologist, OCT, dietician, doctor, nurse, physiotherapist etc.

**Results:** Details of the service and of all referred patients and results from pre- and post EORTC-QLQ-C30 screening of the first 50 patients who completed the programme will be presented.

**Discussion:** This is a description of a pioneer- and pilot project. Further research is needed and a RCT of the service starts up December 2014.

**Abstract number:** P2-249

**Abstract type:** Poster

## An Interdisciplinary Assessment Tool

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A so-called S-analysis supports the interdisciplinary collaboration in a hospice. In this way our work in every respect is grounded in the knowledge of the patient and satisfy the patient's participation, wants and needs. The intention is that the patient experiences that he or she is seen as a human with own thoughts and choices in the last part of life.

To fulfil the hospice philosophy, data was collected in dialogue with each patient regarding to these six categories: Symptom control, Self-determination, Social relationships, Self-image, Synthesis / summation and Surrender.

In this way, we get highly individual scenes, that clarifies who the patient is as a person.

The concepts behind the six S-categories has its origins in the American psychiatrist, Avery Weisman. He pointed out in the 1970s, the importance of a holistic approach and stressed the importance of teamwork and a multidisciplinary approach.

Through his surveys, he revealed and appointed a number of factors that had a decisive influence on the quality of the past life.

Swedish researchers have redefined AW's work and summarised it for the six S's which form a sort of criteria for or guide to a good death and which in turn supports an overall palliative care.

The idea is that the seriously ill and dying people are strongest possible within the six areas that constitute the foundation to provide good quality of the past life. Pathways for patients to obtain the strongest position possible varies a lot and can be extremely complex.

In the hospice context we exploit a broad variety of tanatological items where needed. All professional groups contribute with their knowledge to illuminate the patient's S status. We find, that the S-analysis when conducted interdisciplinarily is a valuable tool which helps us to set the direction for the specific palliative initiatives, each patient can benefit from. An oral presentation will illustrate and broaden this more closely.

**Abstract number:** P2-250

**Abstract type:** Poster

## Cooperation between Nurses and Medical Carers and Other Specialists in Hospices, Nursing Homes and Long Term Care Units in Poland (Pilot Study)

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**Background:** Real collaboration, not merely simultaneous work of different specialists, allows to improve patients quality of life efficiently. Cooperation between nurses and medical carers, who work close to patients, is of a great importance.

This applies not only to palliative care units, but also long-term care and nursing homes, where people who need palliative approach may stay.

**Aim:** We aimed to define the characteristics of cooperation between nurses and medical carers in different places of care. In addition we assessed the specificity of multidisciplinary approach in the hospice care and verified applicability of questionnaire for further research.

**Method:** Diagnostic survey was implemented. Anonymous questionnaire was sent to randomly selected hospices, nursing homes and long-term care units in Poland – one in each district (48 places in total). 136 questionnaires were returned (35% medical care practitioners, 65% nurses) from 16 units.

**Results:** 91% respondents cooperated with more than 3 specialists while performing their duties. Almost equal number of participants claimed to be satisfied with the scope of their duties, as to have too wide one. Analysis of open questions showed that 36% of participants indicated atmosphere in the workplace as important factor of satisfaction with cooperation, followed by organisational aspects (30%) and communication in the team (17%). In hospices, more respondents (91%) cooperated with physicians and psychologists.

**Conclusion:** Hospices differ from nursing homes and medical care units in many aspects of team work. Most participants indicated 'atmosphere' as factor of good cooperation, which is difficult to operationalise. It is necessary to search for methods of providing high level of inter-professional cooperation in different settings of care.

## Education

**Abstract number:** P2-251

**Abstract type:** Poster

## Knowledge and Attitudes of Palliative Care Teams of Oncology Centers in Mexico

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Education is a key element in providing palliative care efficiently in developing countries. A program of basic in training Palliative Care Equipment (PCE) of the major oncology centers state of Mexico with duration of 2 weeks, consisting of doctors, nurses, nutritionists, social workers, psychologists and thanatology was performed.

The aim was to analyse the degree of knowledge and attitudes of PCE and post-training through a survey before and after your workout shape evolution, measuring the degree of progress to the academic activity. 44 surveys PCE and the level of basic knowledge of palliative care were conducted prior to training was 5.7 / 10 8.7 / 10 points respectively, after training. In terms of professional attitudes change importantly of apathy, frustration and uncoordinated work better integration of team members with identification of roles and functions, greater satisfaction with their work and a more integrative approach to cancer patients at the end of life and family in palliative care.



**Abstract number:** P2-252

**Abstract type:** Poster

## Undergraduate Nurse Education in Cancer Care: Investigating the Impact of an Innovation in Curriculum Content and Delivery

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**Background:** Internationally cancer incidence is increasing and treatments are becoming more complex. Undergraduate nurses need appropriate preparation to deliver the supportive and palliative cancer care of the future. UK policy places importance on person-centred, holistic cancer care that supports self-management for improvement of both clinical outcomes and patient experience.

**Aim:** This paper reports the findings of a quasi-experimental evaluation of an innovative educational initiative to enhance undergraduate nurse education in cancer care.

**Methods:** The investigation is a mixed methods quasi-experimental study of the impact of a new practitioner/lecturer role. The study participants include a clinical nurse specialist engaged in curriculum development/delivery and two cohorts of undergraduate nurses ( $n_{\text{control}}=89$ ,  $n_{\text{intervention}}=84$ ) in South Wales, 2014.

**Findings:** Response to questionnaires was >95% at four timepoints. Undergraduate nurses in both cohorts had limited understanding of holistic cancer care and support of self-management. Undergraduates interviewed from the control cohort ( $n=6$ ) emphasised the importance of listening to people with cancer and conflated cancer and end of life care. All spoke about signposting patients to information services but this was their only reference to supporting self-management. Immediately following exposure to a new model of undergraduate education in cancer care the intervention cohort had improved knowledge, confidence in skills and confidence in their ability to support self-management and influence patient experience. Data collection and analysis is on-going and will be complete by Feb 2015.

**Conclusions:** The context of cancer care is changing rapidly. This presents a challenge in the educational preparation of practitioners for the future. This project has tested a new model for the delivery of undergraduate nurse cancer education. Preliminary findings are positive.

**Funder:** Macmillan Cancer Support, Wales

**Abstract number:** P2-253

**Abstract type:** Poster

## Developing and Evaluating Complex Interventions in Palliative Care: Use of e-learning to Disseminate Research Findings

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There is a need to improve research methods to evaluate models of service delivery and complex service level interventions in EoLC and identify good research practice to aid future studies. The Methods Of Researching End of Life Care (MORECare) collaboration was established by the UK Medical Research Council (MRC) MORECare built on the MRC guidance on the development and evaluation of complex interventions. We developed evidence-based guidance on the best methods for the design and conduct of research evaluating EoLC particularly focussing on complex service-delivery interventions, reconfigurations and treatments. We conducted three systematic literature reviews, five transparent expert consultations involving consensus methods of nominal group and online voting, and two stakeholder workshops to identify challenges and best practice in EoLC research, including: participation, ethics, attrition, integration of mixed methods, complex outcomes and economic evaluation which were published individually. The final synthesis of all the data formed the MORECare statement detailing guidance on best practice to undertake evaluative research on EoLC.

We are disseminating the Morecare statement and underpinning work by developing, piloting and evaluating a short e-learning course, consisting of six modules:

- 1) introduction to complex interventions and MRC framework;
- 2) Selection of outcome measures;
- 3) Use of outcome measure;
- 4) Missing Data, attrition and response shift;
- 5) Integrating mixed methods;
- 6) Ethics.

The e-learning resource is designed for clinicians and researchers. Each module consists of a series of reading material, a formal assessment and an interactive presentation (e.g. formative assessment and reflective activities).

The development of this e-learning course consists of 4 stages:

- 1) development and peer review of e-learning content;
- 2) implementation and beta- testing;
- 3) Piloting ( $n=15$ ) on learning and utility
- 4) first intake and evaluation.

Funding: MRC

**Abstract number:** P2-254

**Abstract type:** Poster

## Teaching Palliative Care to the Public: The Last Aid Course – An International Multicenter Project from Norway, Denmark and Germany

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**Aims:** Palliative Care aims for best possible quality of life for patients with chronic life threatening diseases and their relatives. Many people do need Palliative Care all over the world and the demand is increasing due to demographic changes. The public knowledge approach aims to inform and teach the public about Palliative Care. This approach includes last aid courses and a chain of Palliative Care.

**Methods:** The curriculum for an Austrian last aid course which consisted of 16 teaching hours was modified and shortened. An international working group from Norway, Denmark and Germany modified the curriculum and reached consensus about the contents of a short basic Last Aid course. Members of the working group were experts in the field of Palliative care and belonged to different professions: 1 psychologist, 1 social worker, 1 specialist in palliative medicine, 1 priest, 1 physiotherapist, 1 family medicine physician. In addition to these participants experts from other professions were consulted and gave comments on the curriculum.

**Results:** The result is a curriculum for a Last Aid course for the public with 4 teaching hours only. It is divided into 4 modules with 1 hour each (each lasting 45 minutes). It is planned to offer the course both as one-day course or on different days with one or to modules at a time suited for different groups of participants. The themes of the modules are:

1. Care at the end of life,
2. Advance Care planning and decision making,
3. Symptom management,
4. Cultural aspects of death and bereavement.

Pilot courses start from October 2014 and a first evaluation of the concept will take place in march 2015.

**Conclusion:** A curriculum for a basic Last aid course was designed by an international working group. The curriculum will be presented. Pilot courses and evaluation of the concept will start in October 2014 and the first results will be presented at the EAPC congress in may 2015.

**Abstract number:** P2-255

**Abstract type:** Poster

## Increasing the Number of Legal Oral Morphine Prescribers in a Resource Limited Setting

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**Background:** The number of cancer cases especially in low and middle income countries is estimated to double by 2030. In 2009, 200,000 South Africans died with moderate to severe pain (Wilma 2012) and according to Merriman, more than 200,000 Ugandan patients are in need of pain control and yet access to morphine prescribers still remains a challenge.

**Aims:**

1. To equip clinical officers (Medicine Diploma graduates) with the knowledge and skills to prescribe morphine for pain management and to help in integrating palliative care services into the existing health services structure
2. To train clinical officers in providing appropriate palliative care services to patients after doing a thorough pain and symptom assessment
3. To develop the competencies of clinical officers in prescribing morphine and adherence to the necessary legal requirements and practice.

**Methods:** Students were randomly selected from various parts of the country and subjected to class teaching for four weeks and thereafter taken for a two weeks clinical placement in various Hospices and Hospital palliative care units to translate the class theory into practice.

**Results:** A total number of eighty Clinical Officers were trained and equipped with impeccable knowledge of pain assessment and morphine prescription in accordance with national and international guidelines.

**Conclusion:** The training of clinical officers and other health professional that are the primary contacts for the majority of palliative care patients need to be supported and funded by all partners. Countries need to integrate palliative care into their main stream health care services as well as training curricula for paramedics and other health professionals and to stock oral Liquid Morphine at all levels of health care. Other countries can emulate this example to amend their laws to allow specially trained Clinical Officers and Nurses to prescribe oral liquid morphine for palliative care pain management.

**Abstract number:** P2-256

**Abstract type:** Poster

## Pretending to be Dying

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**Introduction:** The benefits of online learning and patient simulation have been extensively studied. These technologies solve a myriad of dilemmas inherent in the Australian context. The tenants of Palliative Medicine: excellent symptom control and communication, optimisation of quality of life, patient-centred decision making and utilisation of the multidisciplinary team are increasingly being seen as vital skills for all doctors regardless of their area of practice. But how do students feel about digitised learning in the palliative care context?

**Aim and design:** To explore the reactions of final year medicine students to patient scenarios presented in video format and to concepts of simulated patients in the teaching of Palliative Medicine. Three focus groups ( $N=22$ ) were provided with a copy of an online-learning package. They were asked to respond to a series of questions in free text. Thematic analysis was used to analyse the data.

**Points for discussion:** This preliminary work indicates that students have specific concerns regarding on-line and simulated patients in the Palliative Medicine context. They expressed a strong recognition of the importance of 'confronting' the issues inherent in palliative care and felt that the digital environment both protected and buffered them from this experience. Students expressed a wish for palliative care to be 'different' from other areas of training and to provide 'real patient' and 'real educator' interaction in a way that they perceived as lacking elsewhere. The students felt unable to 'suspend their disbelief' and effectively respond to actors portraying terminally ill and dying patients. When asked for their preferred teaching method the majority of respondents indicated 'bedside teaching'. This work runs counter to the bulk of current work in this area and poses an important question for further studies and for the Palliative Care community.

No additional funding was utilised for this project.

**Abstract number:** P2-257  
**Abstract type:** Poster

## E-learning – Doodles, Snippets, Mindmaps and Apps: Keeping up with the New Generation

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Mobile information technologies, including tablets and apps, are becoming ubiquitous in today's health care environments. In addition to accessing patient information at the point of care, they also present exciting platforms and opportunities to support just-in-time learning. Peer-reviewed palliative and End-of-Life Care (EOL) courseware and learning materials produced nationally for use across Canada and abroad provide a framework for a suite of products for mobile devices and desktop computers that support distributed learning and clinical decision-making at the point of care.

New e-learning apps will be demonstrated including 'Doodles', 'Snippets', and 'MindMaps'. Doodles are short (1 to 3 minute-long) YouTube-type videos that combine voice-over narration with animated sketching to provide dynamic presentations on topics such as, 'Who provides palliative care?' and 'Better Early than Late'. Snippets are short online modules (2–5-minutes long) on various topics such as, 'Discussing opioid side effects'; often with short videos to demonstrate techniques. MindMaps draw upon cognitive psychology research on how people store information. The interactive maps (available as a website and as apps) use a trunk-branch-twigg format to provide essential clinical tips on the essentials to providing Palliative and End-of-Life Care. These include tips on pain and symptom management, communication, psycho-social and spiritual care.

Upon completion of the workshop participants will:

- Gain an understanding of the Learning Management System (LMS) that supports e-learning apps
- Learn how to access just-in-time teaching/learning e-resources to support best practice bedside care
- Be invited to recommend future Palliative care training e-learning topics.

These resources show promise to support just-in-time learning across the learning continuum, from undergraduate, to postgraduate and professional development, across different disciplines, and mainly at the point of care.

**Abstract number:** P2-258  
**Abstract type:** Poster

## How End of Life Care Facilitators within an Acute Hospital Trust Have Improved End of Life Care through Different Styles of Education

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**Aim:** To improve end of life care through education and training for all health care professionals working within the Trust ensuring that all patients nearing the end of life and those that are important to them do not have care based on 'luck' but is evidence based and delivered with care and compassion.

**Method:** The end of life facilitators in conjunction with the specialist palliative care team have implemented a number of different styles of education in order to meet the needs of all health care professionals working within an acute trust. These range from formal teaching sessions/study days to bespoke one to one adhoc clinical based training. To raise the profile of the educational opportunities on offer, awareness stands and e-learning packages have been implemented.

**Results:** All education provided has been well evaluated and so far 3868 HCP have attended or completed EOLC education over a 2 year period. This has had a positive impact on patient care particularly medication prescribing, documenting preferred place of care and the importance of communication with patients and those who are important to them.

**Conclusion:** The aim of the role was to improve education and training for all health care professionals. The implementation of the facilitator's role within the acute hospital trust has significantly raised the awareness of the need for end of life care education. However there are some inconsistencies in certain areas and the challenge in releasing staff to attend education remains a problem. End of life care facilitators continue to develop innovative approaches to address these issues and will continue to raise the profile of end of life care through education.

**Abstract number:** P2-259  
**Abstract type:** Poster

## Implementation and Evaluation of a Four-year Integrated Palliative and End-of-Life Care Curriculum for Medical Students

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**Background:** Graduating medical students do not consistently feel competent to provide primary palliative care. We created, implemented, and evaluated a four-year medical student curriculum in palliative and end-of-life (eol) care.

**Aims:**

- Create and implement a longitudinal, integrated curriculum to promote the acquisition of primary palliative and eol care competencies.
- Evaluate the effectiveness of the curriculum with a multi-method approach.

**Methods:** Learning objectives were defined for each curricular component which included: seminars; standardised patient and interprofessional workshops; hospice experiences; communication and reflection exercise on clerkships; online interactive modules. A multi-method curriculum evaluation included: analysis of student written reflections and questionnaires; graduating student surveys; demonstration of students' competency in palliative care with a newly created observed structured clinical examination (OSCE).

**Results:** Content analyses of student reflections in experiential components demonstrated meaningful engagement in the learning, with recognition of the complexity of patients' reactions to dying and the value of the clinicians' presence and the interprofessional team. Graduating student surveys demonstrated improvements in many domains of eol care. A majority of fourth year students demonstrated competency in history and communication skills in the palliative care OSCE.

**Conclusions:** This effective curriculum is distinguished by these key features:

- Employs longitudinal, developmentally appropriate, integrated learning
- Utilises many different curricular teaching methods
- Emphasises experiential, skill building activities
- Focuses on student self-reflection
- Incorporates interprofessional learning and faculty
- Includes spiritual and cultural aspects of care
- Utilises online, blended learning

With defined modalities and educational tools, components of our proven curriculum can be adapted for use in existing curricula.

**Abstract number:** P2-260  
**Abstract type:** Poster

## One Chance to Teach it Right: A Response to One Chance to Get it Right

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**Background:** 'One Chance to Get it Right', 2014, outlines 5 Priorities of Care for Dying People in England, highlighting the need for education to deliver high quality care. An integrated specialist palliative care service with designated education team, supports community, hospital & care homes within a well-circumscribed area in the North of England. We describe the educational response to this new guidance.

**Aims:** To provide local priorities of care training to all staff involved.

**Method:** A training package, developed to outline the 5 priorities of care for dying patients, is delivered by a team, within specialist palliative care services, to any staff – health care assistant to consultant, therapist to GP, cleaner to chief executive, across community, hospital & care homes. Strong Trust Executive Board & Clinical Commissioning Groups leadership ensures staff are released for training. Training emphasises the need for clear communication. Further education & support is delivered to reinforce learning following recent changes to the Individualised Plan for Care for Patients thought likely to be Dying. All who receive training are given a colourful handout & certificate of training. Supporting posters are displayed throughout the hospital, community, offices & care homes. Business cards have been developed to remind staff of useful terminology for speaking to patients & families.

**Results:** In the first 3 months training has been delivered training to 1696 individuals – 723 hospital, 392 community & 484 care home staff. We have visited & trained GPs in 76% of local GP surgeries. Training has been well received with a surge of enthusiasm & pride for the end of life care given locally.

**Conclusion:** A large-scale education drive has enabled delivery of Care of the Dying Training to large numbers of staff in a short period. This has made staff aware of their duties & responsibilities & generated a renewed culture where clinical & non-clinical staff strive for excellent care.

**Abstract number:** P2-261  
**Abstract type:** Poster

## What Are the Educational Needs of Palliative Medicine Trainees in the Assessment and Management of Pain in Patients with Dementia?

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**Background:** Pain in patients with dementia (PwD) is often poorly recognised and treated. Although specialist palliative care services are increasingly becoming involved in the care of PwD, little is known about the training needs of palliative medicine doctors in this area.

**Aims:** To assess palliative medicine trainees perceptions of their current skills in the assessment/management of pain in PwD and their perceived educational needs.

**Methods:** An electronic survey was sent to Palliative Medicine trainees with a national training number in the United Kingdom registered with the Association of Palliative Medicine (n=204, response rate 23%). Quantitative data was analysed using IBM SPSS Statistics Version 20 and content analysis was used for qualitative data.

**Results:** Median confidence scores (1–10 scale) for assessing/managing pain in PwD were 6 (IQR 5–8) and 6 (IQR 6–8) respectively. However, only 46% of trainees had received training on assessment, and only 26% having had training on management, of pain in this patient group. An awareness of pain assessment tools for PwD was not associated with higher perceived confidence in the assessment of pain, and only half of those indicating an awareness of tools had actually used them in practice.

Factors shown to have an association with higher confidence levels were:

- the length of palliative medicine experience – for management of pain
- previous experience specifically in elderly medicine and the frequency of contact with PwD – for assessment of pain

**Conclusion:** Palliative medicine trainees have moderate-high confidence in assessing and managing pain in PwD but relatively low levels of training specifically in this area and on the use of pain assessment tools.

Trainees expressed a desire for further training, preferably in a study day setting. Further work is required to determine the content of educational modules and to explore the potential benefits of cross-specialty training days.

## Poster Sessions (Poster Exhibition Set 2)

**Abstract number:** P2-262

**Abstract type:** Poster

### European Palliative Care Academy (EUPCA) – Leadership Course

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**Aims:** The European Palliative Care Academy-Leadership Course is an innovative trans-country postgraduate educational program in palliative care (PC). Participants are trained for future leadership positions to advance PC provision across Europe. The program takes place over 1.5 years and comprises one course week at each of the four European academic institutions in addition to an 'Observation Week' at a chosen institution.

**Methods:** By means of an online survey needs were assessed to inform the content and delivery of the program prior to its commencement. 194 European PC professionals shared their views. Based on these findings, a steering committee comprising partner institution professionals determined course structure and content. They selected 20 participants according to previously determined criteria. Course evaluation was conducted by standardised questionnaires as well as an external evaluator.

**Results:** The needs analysis indicated that the course should be in English and divided into single week modules, run in each of the four countries. The modules comprise Personal Development, Project Management, Teamwork, Research Methods, Advocacy and Local Best Practice of each host country. The participants of the current program include 7 professions from 14 countries in eastern and western Europe (50% each). The 20 participants with their personal projects have already ensured that the first course has enriched PC in Europe. Both internal and external evaluations suggest the programme has been well received.

**Conclusion:** The needs analysis identified a lack of postgraduate training opportunities to promote leadership in PC across Europe. The evaluation illustrated that course structure, organisation and curriculum allow for the achievement of the learning objectives. The results of the evaluations will be used to make necessary amendments for successive intakes. In order to secure long-term sustainability of the programme, further funding partners are being sought.

**Abstract number:** P2-263

**Abstract type:** Poster

### Madrid Training Program: Building Blocks to Bridge and Channel Knowledge and Understanding

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**Background:** Considered a right and a duty, professional development is a commitment shared between organisation and professionals. We set to 'Promote Training, Research, Development and Innovation' to 'Adequate professional, volunteers and carers' education' for which a central training program was developed framed within a model of knowledge management to develop learning abilities and professional development supported by competencies improvement.

**Aim:** To establish the Impact of a Sixto year, centralised, interdisciplinary and free to attend, program for 80000 health professionals.

**Methods:** Descriptive, retrospective and quantitative 6 year period study for a 4 level training program to develop, analysing the qualitative changes in care provision and reckoning number of professionals trained from each of the disciplines involved in End of Life Care.

**Results:** Four level fully interdisciplinary program now in place. Places to attend are sought after. All our SPC teams, hospitals and most independent units and health centers encourage their professionals to attend a) Basic: 20 hours 20 editions attended by over 2000 students b) Intermediate: 40hours 8 editions attended by 240 students c) Consolidation level: 15 hours/ 5 hours, 2 editions, 30 students d) Advanced: 8 hours 16 study days, over 500 students) Expert: 8 hours 4 Study Days, 120 students Disciplines: Doctors, Nurses, Nursing Auxiliaries, Social Workers, Pastoral Care Workers, Psychologists, Physiotherapists, Occupational Therapists and others from Primary, Secondary and Emergency Care. A detailed summary of topics taught, budget available and time.

**Conclusion / Discussion:** Changes have been observed: more integral focus on PC approach, perceived improvement in professional competences at all levels of care, improved communication skills round patient and family related to holistic assessment, ethically sound advanced care planning and bereavement, Preferred Place of Care-Death documented and reduction in complaints.

**Abstract number:** P2-264

**Abstract type:** Poster

### Planning for the Future: Increasing the Advance Care Planning Confidence of District Nurses

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**Aim:** The project is a small scale study of the knowledge, skills and confidence of district nurses to engage in Advance Care Planning (ACP) conversations with palliative patients at

home. A teaching package was delivered to discuss Advance Care Planning and a tool designed to support and documents these conversations to improve communication. This was followed by an evaluation of project and its implications to practice.

**Background:** The End of Life Strategy (NHS, 2008) identified the lack of open discussion between health and social care staff, those approaching the end of life and those who care for them, as one of the key barriers to the delivery of good end of life care. The literature review supports the evidence that ACP should be integrated at end-of-life discussions and that good communication is the corner stone of a therapeutic relationship with the patient and their family. ACP is a process which emphasises the quality of life, therapeutic communication and value patients autonomy.

**Method:** Quantitative data was collected using questionnaires and auditing current practice. The delivery of an advance care plan presentation and introduction of a documentation tool was initiated followed by post analysis and evaluation of its impact in the advance care planning process.

**Results:** The initial data identified the district nurses had either not received training and/or had reduced confidence in implementing the principles of advance care plan communication. Following the project the data revealed the positive impact the tool and support/training provided had on the district nurses approach to advance care planning. DNs recorded number of patients had been given an ACP pack increased from 30% – 70%; those with ACP discussion from 20% – 70%; those whose wishes & preferences were reviewed from 30%–90%; those with other items from 0–10%; patient & carer wishes revisited in last days 45%–100%.

**Conclusion:** All aspects of ACP discussion & documentation had improved considerably.

**Abstract number:** P2-265

**Abstract type:** Poster

### Community of Practice: Developing a Cross Boundary Community of Learning for End of Life Care

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**Background:** It was planned to make community & hospital Band 6 nurses within the Trust responsible for End of Life care. In order to prepare them for and support them in this new role they formed a Community of Practice led by Specialist Palliative Care Services.

**Aims:** To improve the quality & experience of End of Life Care for all patients & families, across the trust.

**Method:** Gained support from Director of Nursing & Trust board to drive this 11 month initiative. These influential Band 6 nurses leaders from all areas of the ICO joined together have met monthly to learn, enthuse, support one another, share good practice, and encourage the promotion of good End of Life care within their own work areas. All undertook the End of Life Skill Set Challenge development programme and are auditing End of Life practice within their own area. Celebrated their successes at the end of the year.

**Results:** The programme will be completed by the end of the calendar year. Achievements to date include audit of spiritual needs assessment with a resulting development of a Spiritual Care Plan for use across the Trust, improved working relationships between hospital & community staff, audits spanning every aspect of End of Life care from medication to conversations about dying. This presentation will include the number of staff who complete the End of Life Skill Set Challenge, a summary of the End of Life audit results, qualitative & quantitative feedback from participants undertaken independently by local university staff.

**Abstract number:** P2-266

**Abstract type:** Poster

### Evaluation of Palliative Care Education in Japanese Pharmacy Students

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**Background:** Palliative care education for pharmacy students and pharmacists is now developing in Japan. We initiated lectures about palliative care pharmacotherapy for undergraduate pharmacy students in Hokkaido Pharmaceutical University from 2010, and took the lead in palliative care student education nationwide. Our prior study showed significant increase in knowledge about palliative care just after the lectures among the students.

**Aim:** Our aims of this study are to estimate the long-term changes in knowledge about palliative care in pharmacy students through lectures and clinical trainings and evaluate the efficacy of our educational program.

**Method:** Our palliative program consisted of essential 15 lectures for 5 grade pharmacy students. We followed pharmacy students who took palliative care lectures until they finish clinical training about 18 month later. We compared scores of Palliative Care Knowledge Test (PCKT) which include 20 questions in five domains including [philosophy], [pain], [dyspnea], [psychiatric problems (delirium)], and [gastrointestinal symptoms (nutrition)] before palliative care lectures and after clinical trainings.

**Result:** The mean total score of PCKT increased from 10.0 (standard deviation (SD) 3.3) to 10.8 (SD 2.4) among 87 students, but it was not statistically significant. More than 90% of students answered correctly for questions about philosophy of palliative care. However, even after lectures and clinical trainings, proportion of correct answers was lower than 20% or the score was decreased from before lectures among some questions about [dyspnea], [psychiatric problems (delirium)], [gastrointestinal symptoms (nutrition)].

**Conclusion:** This study showed most of the Japanese pharmacy students had correct knowledge of palliative care philosophy. However, our palliative care educational program that was mainly based on lectures had limitation to teach some specialised knowledge.



**Abstract number:** P2-267

**Abstract type:** Poster

## Physician Trainees' Perceptions of Palliative Care Education and Training – An Illuminative Evaluation

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**Background:** In the UK most palliative care occurs in acute hospital settings, delivered by non-specialists physician trainees including Core Medical Trainees (CMTs). Most have not received specific postgraduate palliative care training. Little is known about physician trainees' perceptions of palliative training.

**Methods:** This unprecedented study takes a social constructivist approach informed by illuminative evaluation methodology. Eleven semi-structured interviews with CMTs in a UK University hospital were undertaken between May–June 2014. Content analysis of interview transcripts generated themes. Respondent validation and investigator reflexivity ensured reliability. Ethical approval was granted.

Aims were to describe trainees satisfaction with training, perceptions of good and bad learning experiences, and confidence levels in curriculum palliative competencies.

**Results:** Formal training was lacking; satisfaction was low, but comparable to other curriculum areas. Experiential, informal learning provided most training opportunities and was a feature of good learning experiences. Interaction with hospital palliative care teams, senior physicians and experience in certain specialties was important. Greater clinical experience positively correlated with trainees' perceived confidence in curriculum competencies. Most confidence was expressed in pain and symptom management, completing death certificates, referring to the coroner, and discussing resuscitation status. Least confidence was expressed with: advance care planning, assessment and management of psychological and spiritual needs, agitation anxiety and depression, knowledge of spiritual care services. Findings are supported by the wider literature and may be applied to other Western healthcare settings.

**Conclusion:** Future educational interventions should be targeted towards areas of least confidence. Consideration should be given to mandatory attachments to palliative care specialists for physician trainees.

**Abstract number:** P2-268

**Abstract type:** Poster

## New Colleagues – Former Students. Spreading Palliative Care Knowledge among Nursing Students

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**Background:** Our aim was to prepare nursing students to care for dying patients during their clinical practice and also create a good learning environment. We wanted a supportive environment that enabled safety and strength to the students to engage in existential dialogue and sometimes difficult situations with patients in end of life care. A pedagogical project was initiated in a palliative care unit in Stockholm, with funding's from the county council and the aim to spread palliative care knowledge. Focus was on high quality clinical practice, both theoretical and practical, in the palliative learning environment.

**Method:** We choose to collaborate with two universities profiled in higher nursing education in palliative care. The nursing students had a four week clinical practice in our unit in the fifth semester of their education while they also attended a university course in palliative care. Further the direct patient care the students attended a theoretical day with lectures by different palliative care team-members, primarily nurses. The lecturers addressed reality-based patient cases, severe symptoms of terminally ill, existential support, bereavement and teamwork. Daily reflection was an important learning-aspect and in the end of practice the students participated in an one hour semi-structured reflection, led by a nurse, where they were able to express difficulties, and reflect on expectations for their clinical practice in palliative care.

**Results:** The student evaluations were very positive, regarding tutoring, learning-environment and an increased awareness for palliative care.

**Conclusion:** Our aim to offer a clinical practice in integration with direct patient care, theory and reflection has turned out to be a success, both for the students and the nurses – both the tutors and their colleagues. The work to spread palliative care knowledge continues, and the greatest success of all is that a number of former students are now our colleagues.

**Abstract number:** P2-269

**Abstract type:** Poster

## Inter-professional Education in Palliative Care. Educating across Sectors in Palliative Care

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In 2011, the Ministry of Health recommended that the education standards for palliative care be raised to a higher level for all basic professional groups.

Due to the increased costs for continuing education, few institutions or hospitals can afford to send only a few of their staff members to educational enrichment courses. The education programmes offered are mostly targeted to one specific profession.

**Aims:** Constructing an education model in which

(1) the courses become a shared experience for different inter-professional participants, and (2) that the chosen topics of the courses are combined so the participants will experience palliative care as an inter-professional approach to the patients and their families.

The mixed groups of participants increase their ability to integrate the benefits of the courses and tailor them for their specific institutional needs.

The courses should be offered for every health centre, nursing home or hospital unit.

**Method:** Preparing an education programme weighing equally medical palliative issues and issues concerning the whole life of the patients. The education topics are chosen by the participants beforehand according to their specific needs. The courses are for free.

**Results:** 20–40 people attend each course. The duration of the courses varies from 2–3 hours to a full project day. Within the first year of the project, 596 have participated in the education programme: Hospital doctors, general practitioners, nurses, home helpers and physiotherapists. There are 250 participants for autumn 2014, i.e. 100 district nurses, and all

priests from the local deanery.

**Conclusion:** The demand for courses is significant and the initiative has been well received by the participants. The course benefits are most successful if the education programme weighs equally medical and non-medical palliative issues.

Group: The education topics have been prepared as a collaboration among inter-professional staff from two different organisations.

**Abstract number:** P2-270

**Abstract type:** Poster

## Providing and Sharing Information and Consultations for Cancer Treatment and Care in the City Street

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**Background and aim:** In this study, we provided information and consultations outside in town. The aim of this action is giving more cancer related knowledge for many cancer survivors and citizens. The results are reported below.

**Methods:** We planned the programme in Sapporo's Underground Pedestrian Space on Saturday. There were 70 volunteers to implement it, including physicians, nurses, case workers, cosmetic camouflage makeup therapists, peer supporters, and Hokkaido prefectural employees. The programme included the following:

1. Information on and coping strategies for side effects of therapy

2. Consultations with experts and peer supporters

3. 15 minutes lectures about pain relief, home healthcare, and nutrition for cancer patients

4. Supplying the brochures to disseminate information on cancer and palliative care

We aggregated participants' questionnaire responses and the consultation records

**Results:** There were about 1,000 attendees that day. We collected questionnaires from 98 respondents and aggregated the consultation records of 45 people. Of the attendees, 40% came 'in passing', 50% were family members who had from cancer, and 30% were cancer survivors. The respondents' ages ranged from 40s to 70s. Of the consultants, 70% had cancer, 20% were family members, and 10% were friends of cancer patients. The most prevalent topic during the consultations was treatment from side effects (30%), while other topics discussed in the consultations included decision-making regarding cancer therapy and how family members can offer support to patients.

**Conclusion:** We provided information and consultations on cancer in the street. We received more attendees come across the street than we expected who required more knowledge of cancer. We realised the necessity for place where people can feel free to go for a consultation.

**Abstract number:** P2-271

**Abstract type:** Poster

## The Role of an End-of-Life Training Workshop for Care Staff in Improving End of Life Care

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Formal training evaluation, using a Kirkpatrick framework, of end-of-life (EOL) care for residential care settings would help in improving education approaches. Study aim: To identify if workshop training made a difference over time to participants' values, practice & sense of job satisfaction.

Design etc.

A mixed-method design was used; 4 community hospitals were purposefully sampled – in each at least 20 participants attended training in 2012/13, & settings were rural & urban. The following data was collected:

(i) same-day evaluation sheets examined 'Participant Reactions'

(ii) Questionnaires assessed 'Learning & On-the-Job Behaviour' 3–12 months post-workshop

(iii) Focus-group discussions (fgds) assessed 'Learning & On-the-Job Behaviour' 3–12 months post-workshop

(iv) Interviews with Nursing managers assessed 'Results/ Impact and Challenges' 4–16 months post-workshop.

Descriptive statistics & themed analysis of interview/fgd data were performed.

**Results:** EVALUATION SHEETS (151 participants): 85% rated workshop as 'excellent' on a 4-point scale (excellent-good-fair-poor), & 14% rated it as 'good'.

QUESTIONNAIRES (29/151; 19% response rate): Respondents reported increased confidence/ more openness to discussing EOL with residents & found format of training workshop very good.

FGDs (n=3, 23 staff): Training was effective in emphasising communication & sensitivity towards residents/families. Staff reported changed attitudes, increased confidence in engaging with residents/families, & felt more competent.

INTERVIEWS WITH MANAGERS (n=7): All very positive about this training. Workshop success attributed to on-site location, multi-disciplinary, expert external facilitators. Barriers included staff shortages & budget cuts & high staff turnover.

**Conclusion:** Survey response rate at 12 months was poor. Qualitative report showed training was worthwhile & highly motivating, & led to attitudinal change & behaviour change according to managers & participants.



**Abstract number:** P2-272

**Abstract type:** Poster

## Palliative Care (PC) Education and its Importance in Providing a Quality Service

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**Goal:** To present; the work of Mary Potter team over the years being made on the continuing education of healthcare professionals on PC; Highlight the positive impact of the education on the daily work of doctors and nurses; To provide a clear view of the method used for the education; To show the plans regarding the future organisation of these trainings; to discover the impact of the education of healthcare providers on the quality of life for all the patients in need

**Methodology:** For this presentation we have used: Data gathered in Mary Potter PC center which provides PC education for healthcare professionals from the entire country; Questionnaires filled by participants of the residential courses before and after training, reports and notes left in the book of impressions; Training programs; Information collected from patients and their caregivers.

**Results:** Since 2007 Mary Potter PC Center has organised trainings in different formats lasting 1 day, 2 days and 5 days (residential courses, for physicians, nurses, social workers and psychologists from the entire country). All the training were recognised and accredited by the National Center for Continuing Health Education. The trainings were positively evaluated for the organisation, topics selected, methods applied to deliver the information and the overall importance of the trainings. The practical experience has been assessed as the most valuable experience of this activity. Indirect beneficiaries in these trainings are patients who are being modestly provided with PC from healthcare professionals trained in MP center.

**Conclusions:** Education is an important component of PC which needs to develop along with this service. Capacity building of healthcare professionals on PC has produced a positive impact on the care provided to patients and their families. PC education has contributed to the promotion and further development of this service in Albania.

**Keywords:** Education, Palliative care, Healthcare professionals

**Abstract number:** P2-273

**Abstract type:** Poster

## For Integration of Palliative Care in Critical/Intensive Care Settings

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While delivering Palliative Care (PC) in Critical/Intensive Care Settings (CICS) the physicians and nurses usually follow their 'scant' knowledge in PC and traditional motivation to 'cure' the patient or 'postpone death', which leads to neglecting or missing the opportunity to attend the needs and attitudes towards the care of patient's family and more severely, of the patient him/herself.

The presented research proves the necessity and importance of special education/training of CICS medical staff and integration of PC into CICS at the hospitals of Georgia.

Conducted research was based on the analyses of:

1. Structural interviews of 57 CICS physicians and nurses evaluating their knowledge and skills necessary for conducting of adequate PC;
2. Semi-structural interviews of 23 individuals aged more than 80 years (age range 83–92 years) and 32 advanced cancer patients (age range 32–78) who still continue active life and/or intellectual work.

The first study has evidenced that more than 84% of medical staff working in CICS do not have adequate knowledge and skills needed neither to deliver quality PC for patients nor to communicate effectively with patients and their families.

The second study has shown that more than 70% of needs and attitudes towards the care of these cohorts, recognising the limited terms of their life, is consistent with the 3<sup>rd</sup> and 4<sup>th</sup> levels of A. Maslow pyramid of needs. It was suggested, that such needs and attitudes should be maximally taken into account by medical staff even when the adequate communication is complicated or impossible due to the patient's health state in CICS. The obtained results confirm the importance of education/training in basic PC of medical professionals, working in ICCS.

To support the integration of PC in CICS, two versions of basic PC modules with both – communicative and online-based teaching tools were prepared, accredited and implemented specifically for CICS physicians in Georgia in 2014.

**Abstract number:** P2-274

**Abstract type:** Poster

## Advanced Training in Palliative Care: 15 Years of Experience in Catalonia (Spain)

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**Background:** Advanced training and education in palliative care (PC) is essential for the development of high quality PC delivery. The Catalan Institute of Oncology launched the first Master in PC in 1998. Ten editions have already been completed. The master is been offered by the University of Vic in collaboration with University of Barcelona (Barcelona, Spain).

**Aims:** Describe the quantitative results and evolution of advanced training in education in Palliative care in Catalonia at its 15 years of implementation.

**Methods:** The structure and contents evolution of the master are revised and the participants' professional background, work place, experience, and satisfaction degree in regards to the master are described.

**Results:** More than 400 professionals, 60% physicians and 40% nurses, from diverse settings (hospital, home support teams and socio-health units) have been trained by the master. The master started as modules of 42 academic credits and, since 2010, into subjects and 60 European Credits Transfer System to adapt to the European regulation for superior education.

The teaching syllabus is organised around three core concepts: care philosophy; clinical situations management; and personal work. Additionally, training contents are recently focused on chronic advanced patients and end-of-life care.

Mainly of the students of the last 3 editions did not work exclusively in PC services. They seek to improve their clinical knowledge in regards to symptoms control and to develop better skills as for emotional issues of PC delivery. Their level of satisfaction was 4 out of 5.

**Conclusions/discussion:** Advanced training and education helps professionals to improve their clinical skills and knowledge as for advanced chronic care. The learning outcomes obtained at the Master of PC, based on case report methodology, are the foundation for professional accreditation and advanced career development in the context of PC.

**Abstract number:** P2-275

**Abstract type:** Poster

## Implementation of an Education Program in Palliative Care among Nursing Students: An Action-research Project in the Outermost Region of the Azores

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**Background:** Most courses leading to a nursing degree do not meet the recommendations of the European Association for Palliative Care in palliative care. This may led to difficulties when caring for patients with palliative care needs. In outermost regions, investing in education is a keystone to ensure palliative care provision for all citizens.

**Objectives:** To study the impact of an optional education program in palliative care among nursing students in their

- (i) knowledge,
- (ii) attitudes towards patients and families, and
- (iii) emotional coping.

**Methods:** Research-action. Data was collected using the following instruments: pre and post-education program questionnaire; field-notes of the participant students and course leaders; written reflections provided by the participant students during the practicum that followed the course completion; focus groups with students after the same practicum. Questionnaires were analysed comparatively; content analyses were done inductively to the transcripts of field-notes, written reflections and focus groups. 24 nursing students participated in this study.

**Results:** After the course completion, the students exhibited a more accurate and broader concept of palliative care. The major impact of the course on the students' attitudes towards patients and families referred to an improvement in the students' ability to identify palliative care needs and to better communicate. The course had a major impact on the awareness of students concerning their emotions. Also, the students became more able to cope with difficult situations (e.g., end-of-life care and decisions).

**Conclusions:** The education program in palliative care contributed significantly to students' clinical practice, namely in terms of an increase of self-confidence while caring for terminally ill patients. By participating in this course, students expanded their knowledge on palliative care, which had an impact also in the development of their competences.

**Abstract number:** P2-276

**Abstract type:** Poster

## The EAPC Steering Group on Medical Education and Training: Development of Two New Taskforces

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**Aim:** The EAPC Steering on Group on Medical Education and Training (SG-MET) has been established to oversee a number of specific task forces which look to advance understanding, application and developments in the field. These include: Undergraduate and Postgraduate Curriculum Development; Mapping of Medical Education across Europe; Mapping of the Specialisation of Palliative Medicine; and Research on the preparedness of newly qualified doctors to practise palliative medicine. This paper will outline the development of two new taskforces of the SG-MET.

**Methods:**

**Taskforce 1: Development of a competency based multiprofessional and societal curriculum for care of the dying in the last hours or days of life.**

International consensus to develop a multiprofessional and societal curriculum in care of the dying is required to effectively provide education and training to manage the challenges posed by the projected increased morbidity and mortality in Europe and beyond. The development of a multiprofessional curriculum and a separate societal curriculum will draw on the work of previous EAPC Taskforces on the care of the dying, and the findings from the European Union 7<sup>th</sup> Framework funded OPCARE9 project.

**Taskforce 2. International study of Medical Education in Palliative Care – National Assessment (IMEP-NA).**

Following the successful pilot work conducted by the IMEP taskforce ([www.mcpcil.org.uk/media/24441/eapc%2015.pdf](http://www.mcpcil.org.uk/media/24441/eapc%2015.pdf)), a new Taskforce project will seek to use the existing methodology to conduct national framework assessments of the preparedness of newly qualified doctors to practice palliative medicine in three countries (Spain, Germany and the UK). This project will look to establish an electronic data collection and reporting platform, which can then be expanded to include further countries on completion of the project. In addition, the taskforce will monitor evolving projects in China, India and the USA which are replicating the original IMEP pilot work.

**Abstract number:** P2-277  
**Abstract type:** Poster

## Patients and Families Information Needs Regarding Palliative Care

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**Background:** In Romania, due to cultural particularities and slow development of palliative care, the family plays a major role in the care process at end of life. The Romanian Palliative Care Strategy has as first level of care in the strategy education and support for self-care. To implement the strategy in our area an *Information & Education Center in Palliative Care for Patients and Families* has been set up. The center offers: weekly self-care courses, private counseling, online and printed materials.

**Aim:** To identify the aspects of palliative care on which patients and families would like to receive information and the preferred ways to receive information.

**Method:** A prospective cross-sectional survey, using a purposely developed, face to face administered questionnaire with 20 items. The questionnaire was piloted on patients and family members in day care (alfa Cronbach=0,77). After adjusting it was made available to all patients and family members attending our day center and outpatients clinic during July – September 2014.

**Results:** From 73 distributed questionnaires, 67 persons responded (91.78%). Among them, 80.6% were patients and 19.4% family members, women 71.6%; men 28.4%; main age group was 40 to 59 years old. The main information needs identified: modalities to offer emotional support 68.7%; methods to cope with stress and anxiety 59.7%; evolution and prognosis of the disease 55.2%; treatment options 55.2%; pain treatment 50.7% and information related to communication, life style, nutrition, care and social rights. The preferred ways for information were: counseling/meetings with a health care professional 70.1%, group meetings with patients that have the same diagnosis 41.8%, printed information materials (brochures, books) 34.3% and less the internet.

**Conclusions:** Direct communication by professionals, psycho-emotional aspects of care, existing treatment options and pain therapy are priority issues for respondents in our study.

**Abstract number:** P2-278  
**Abstract type:** Poster

## Constructing Professional Development in Hospice Rookies. How Do we Measure Growth?

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**Aims:** The aim of this work is to ensure that newly appointed hospice staff can develop the skills to deliver specialist palliative care and demonstrate professional development.

**Approach taken:** It is wise for voluntary sector hospices to demonstrate to financial donors and service commissioners that the care provision is value for money, specialist and delivered by a competent workforce.

Newly qualified staff, experienced staff new to palliative care and those wishing to advance to senior positions, need development programmes to support the changing demographic of the dying in England.

Systems to measure professional growth are integral to the design of new development programmes. The concept of '70:20:10' (Jennings, 2013) suggests that most professional learning takes place 'on the job'. Options to demonstrate professional growth include the use of knowledge audits before and after learning opportunities, coaching records, feedback on observed practice, reflective writing, learning contracts and assessment of clinical competence.

**Results:** Audits indicate levels of knowledge and skills, written assignments demonstrate learning, reflective pieces show progression, portfolios of evidence illustrate acquisition of clinical skills.

Some practitioners maximise the opportunities to learn, as shown in well-written assignments and projects that change their own practice and that of their colleagues. Many access the support of the education team to develop self-directed learning skills, with mixed results.

**Conclusion:** Professional growth relies on the engagement and ability of the individual and the range and quality of the learning activities. Measurement of professional growth relies on a range of appropriate tools. In order to deliver specialist palliative care, a hospice must have an open and supportive culture that actively promotes a learning environment to bring about professional growth.

Jennings, Charles 70:20:10 Framework Explained 2013.

**Abstract number:** P2-279  
**Abstract type:** Poster

## 'Learning at the Coalface' – Evaluating Graduate Medical Students Experiences Following Placement at an In-patient Specialist Palliative Care Unit

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Limited exposure to dying patients & those with advanced incurable illness has been highlighted as a potential limitation of undergraduate medical curricula. Optimal symptom management within this patient cohort & provision of end of life care has also been identified as an ongoing learning need by newly qualified doctors.

We sought to elicit experiences & attitudes of graduate medical students following placement at an in-patient hospice unit with view to informing further educational input & curricular development.

At placement conclusion, attending 3rd/4th year medical students were invited to complete questionnaires rating aspects of their experience on 5-item Likert scale with additional qualitative feedback sought in narrative format. Qualitative data was subsequently analysed independently & grouped into broad themes.

25 questionnaires were returned with substantial representation from 3rd year students (68%, n=17). Despite initial reservations, students largely valued the opportunity to engage with patients with life limiting illness, gaining an appreciation of multi-dimensional impact of illness upon their life and pivotal role of interdisciplinary communication and teamwork. 56% (n=14) rated their clinical skills as improved, 60% (n=15) felt their learning would

benefit them in examination settings with the majority (88%, n=22) gaining a clearer understanding of the nature of palliative care. 72% (n=18) judged their attitude to hospice as being positively influenced following placement. Emergent themes included the supportive hospice environment and applicability of learning to other clinical settings .Ongoing learning needs in relation to pain assessment, ethical dimensions of care provision and communication skills were identified as targets for future educational interventions. Medical students deem hospice placement to be a fulfilling, relevant and worthwhile experience contributing positively towards their clinical knowledge and skill base.

**Abstract number:** P2-280  
**Abstract type:** Poster

## Narratives in Palliative Care: Searching for Interdisciplinarity

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Palliative Care, the interdisciplinarity becomes critical to deliver a quality care, especially at the end of life, which is so complex.

Therefore, in the Postgraduate Course 'Palliative Care Model for Comprehensive Health Care', developed in São Paulo, Brazil, narratives was used as a teaching strategy.

After a multidisciplinary workshop, the students produced the life histories of the institution's employees. And so: physicians, physiotherapists, nurses and other health professionals interviewed butlers, housekeepers, construction workers and other non-technical professionals.

The main objectives of this activity were: hearing and sharing stories of people who are sometimes invisible in hospitals and health institutions; decrease the hierarchical distance between top-level professionals and those without technical training; provide students the experience of collecting life histories and production of narratives.

36 narratives were produced, which were presented to all the hospital staff. The students drew a poster that contained the story of the interviewee, a photo and a striking phrase from the interview. The posters were displayed in the auditorium and each student made a brief oral presentation. All respondents participated in the presentation that ended with a brief celebration conference.

We evaluated that the objectives have been achieved; and a second phase of the project it's been developed in the second half of 2014, focusing on the nursing staff at the technical level.

**Keywords:** interdisciplinary team; life histories; education; Palliative Care

**Abstract number:** P2-281  
**Abstract type:** Poster

## Spiritual Care Training Provided to Healthcare Professionals: A Systematic Review

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**Background:** This systematic review is conducted to assess the outcomes of spiritual care training. It outlines the training outcomes based on participants' oral/written feedback, course evaluation and performance assessment. Intervention was defined as any form of spiritual care training provided to health care professionals studying/working in academic or/and clinical setting.

**Method:** Online search was conducted in MEDLINE, EMBASE, CINAHL, Web of Science, ERIC, PsycINFO, ASSIA, CSA, ATLA and CENTRAL to 2013 Week 27 by two independent investigators to reduce error in inclusion. Only peer-reviewed journal articles reporting on training outcomes were included.

**Results:** Primary keyword driven search found 4912 articles, 46 articles were identified as relevant for final analysis. The narrative synthesis of findings outlines following outcomes:

- (1) acknowledging spirituality on individual level,
- (2) success in integrating spirituality in clinical practice,
- (3) positive changes in communication with patients.

**Conclusions:** This study examines primarily pre/post-effects within a single cohort. Due to average study quality the reported findings in this review are to be seen as indicators at most. Nevertheless, this review makes evident that without attending one's own beliefs and needs, addressing spirituality in patients will not be forthcoming. It also demonstrates that spiritual care training may help to challenge the spiritual vacuum in health care institutions.

**Abstract number:** P2-282

**Abstract type:** Poster

## Nuts and Bolts at the Coalface

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**Background:** Accessing ongoing post graduate education continues to be a challenge for some nurses working in rural areas despite proliferate online programs being developed in recent years. In some regional and remote locations internet access may still be unreliable or unpredictable. Low staffing levels at rural health services can contribute to nurses not being able to have study leave. And the cost of travel can be prohibitive in attending education programs at metropolitan centres.

**Aim:** This study evaluated a three day face to face short course in palliative care tailored to the needs of rural nurses and facilitated in two regional communities in 2013.

**Methods:** A mixed qualitative and quantitative study. Pre and post course questionnaires were completed by the attending nurses. The questions were structured on a five point Likert scale recoding the level of knowledge of 13 different aspects of palliative care provision. The completed questionnaires were analysed using SPSS version 21 to obtain p values. The course content was assessed using a survey employing a 1–10 scale with 1 being the least favourable and 10 being the most favourable. These results were collated using descriptive analysis and additional comments grouped into common themes.

**Results:** Twenty-six nurses with a range of qualifications from midwives, registered nurses to care workers attended the short course. Confidence levels ( $p < 0.001$ ) ranged from -4.398 pre course to -8.207 post course in knowledge base. The course content was rated between 6–10 by all the nurses in range of topics covered, applicability to workplace, comprehensiveness and resources utilised within the course delivery.

**Conclusion:** Providing face to face education is an accessible and affordable mode of professional development for rural nurses. Into the future training institutions need to aspire to providing mixed delivery modes of education and consider taking some programs to rural and remote centres.

**Abstract number:** P2-283

**Abstract type:** Poster

## Reported Impact of Commissioning Community-based End-of-Life Care Education: A Qualitative Inquiry

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**Background:** In England, Clinical Commissioning Groups commissions' delivery of end-of-life care education programmes for community based health and social service providers to enhance the skills of the workforce to deliver higher quality end-of-life care. However, little is known about how this educational programme impacts in terms of its quality (valuing palliative care and confidence around delivery of EOLC), scope and impact on service users (patients and families who use the service).

**Aim:** To explore and critically examine stakeholders' views and perceptions concerning the community-based end-of-life care education.

**Methods:** With relevant approvals, in total of 11 in depth, semi-structured interviews and one focus group ( $n=3$ ) were conducted with providers who had delivered (community palliative education team and hospice based palliative education teams) or received (community based district nursing staff and ambulance services) this end-of-life care education. Transcribed Interviews were analysed by using framework analysis.

**Findings:** Clinical practitioners and educational providers were highly positive about the existing end-of-life care education provision. Focused education on facilitating choice around place of care during the last days of life reported to led reduced hospital admissions particularly from care homes at community level. Yet, lack of academic credit and non-protected time for completion of this educational provision were viewed as challenges by healthcare professionals.

**Conclusion:** Commissioning for continued educational and clinical support in end-of-life care provision is essential to enable clinical practitioners to uphold quality in end-of-life care provision. This study found that without continued funding, service providers perceived that the provision of education to support end-of-life care would lose its current momentum and be detrimental in the longer term in achieving quality in provision of end-of-life care at community level.

**Abstract number:** P2-284

**Abstract type:** Poster

## Evaluation of High-fidelity Simulation Training in Delivering Palliative Care Education to Final Year Medical Students – A Pilot Study

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**Introduction:** Established evidence suggests that most newly qualified doctors feel insufficiently prepared to provide end-of-life care. A problem facing medical students is the very little hands on training received in dealing with the dying. Simulation has been extensively used in teaching the management of acutely ill patients. Its use in delivering palliative care education, however, has never previously been assessed at an undergraduate level in the UK.

**Methods:** Final year University of Birmingham medical students ( $n=13$ ) on placement at Good Hope Hospital were randomly allocated to a group that received a day of simulation teaching ( $n=6$ ) and a group that received a 'standard' palliative lecture followed 10 days later by a day of simulation teaching ( $n=7$ ). Each student participated in a simulation scenario individually. Pre and post session questionnaires including free text responses and visual analogue scales (VAS: 0–10) assessing self-reported confidence across a range of palliative care competencies were collected and analysed.

**Results:** Only 15% of students thought they had previously received sufficient palliative care teaching. Post-simulation, mean self-reported confidence levels across all sampled palliative competencies as assessed by VAS had improved. Additionally, the lecture group's self-

reported confidence increased further still following simulation than it had following the lecture. Students rated the simulation as a very useful technique, particularly valuing the hands-on practical experiences in end-of-life communication skills and pharmacological symptom control.

**Conclusion:** The innovative use of undergraduate palliative care simulation has the potential to foster effective learning in a more realistic yet safe and controlled environment, where direct feedback may be given on management of a simulated patient scenario. This confers several advantages over more traditional methods. A larger study is required to further evaluate our initial findings.

**Abstract number:** P2-285

**Abstract type:** Poster

## Building Bridges of Knowledge 'Palliative Care' – A Collaborative Project between Hospice and Nursing Homes

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A study of the palliative care on the municipal level draws attention to the fact that social and healthcare assistants (SHA) lack knowledge about palliative care. Only a small group of the terminally ill and dying needs specialised care at the hospice, which underlines the importance of maintaining a certain quality in the basic palliative care in the municipality.

**Aim:** To transfer knowledge and experience from the hospice sector to the nursing homes.

**Purpose:** To enhance the knowledge and qualifications within palliative care of the SHA.

**Method:** A qualitative study. 40 SHA participated in a course about palliative care where skilled personnel from Hospice taught. An assessment of the course was made with a response rate at 67.5%. Data was obtained from the municipal care system on the 25 citizens who died 6 months prior, during and after the course at the nursing homes taking part of the study.

**Results:** The assessment showed that the SHA:

Have strengthened their palliative qualifications by an enhanced understanding of and knowledge about relief and prevention of suffering

Express good conditions for reflection in the workplace, while other express dissatisfaction

Use work methods that can strengthen the quality of the palliative care, ex a palliative detection schedule and a communications tool

Are better at documenting observations

Can estimate the need for involving a nurse or doctor

Have improved the collaboration with the relatives

**Conclusion:** The SHA professional and palliative qualifications have been strengthened and they are qualified and confident in their work. The progress is backed up by good support from leaders and through preparation of municipal palliative guidelines. This help the implementation of tools, a reflective framework, improved documentation and a continuous focus on strengthening the collaboration with relatives and colleagues. This is a prerequisite for developing the quality of the palliative patient care.

**Abstract number:** P2-286

**Abstract type:** Poster

## Using the European Association of Palliative Care Educational Competencies to Develop an Online Academic Award in Cancer and Palliative Care

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**Background:** Palliative care is provided in many settings and as such members of the care team need the knowledge and skills to enable them to provide optimal palliative care within their role. The European Association for Palliative Care White Paper provides 10 core competencies to help educators, service providers and professionals appreciate the knowledge and skills that are required in order to provide such care. In addition the guidance recommends the development of structured inter-professional education programmes, which are defined by the level of responsibility the professional has within their service.

**Aims:** This presentation discusses how one university utilised the EAPC competencies to develop a new, multi-professional Masters level award in cancer and palliative care.

**Design:** The EAPC competencies were mapped by the palliative care academic team to the principles and ethos of palliative care and other current guidance to ensure this new award contained the requisite information. The content of the modules of learning namely; Contemporary Issues in Cancer and Palliative Care, Advancing Communication, Symptoms in Advanced Disease and Psychosocial Concerns was then developed taking into account the academic level of delivery. Finally the pedagogy was developed to ensure it was commensurate with the level of qualification and the online delivery methodology.

**Results:** This programme of study is now delivered fully online and is available to all members of the multi-professional team who work a cancer or palliative care setting where a core part of their role is caring for such people and their families.

**Conclusion:** The programme is in its infancy but indications from stakeholders involved in its development and current students is that it meets the needs of cancer and palliative care providers as well as individual clinicians working at a more senior level.



**Abstract number:** P2-287  
**Abstract type:** Poster

## Evaluation of Multi-medical Staff Education for Death Related Care in Rural Areas

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**Background and aims:** Palliative care is generally accepted in Japan due in large part to government initiatives during the past ten years. However, a large number of medical institutions in rural communities do not due to complicated cultural issues involving EOL treatment. Our aim in this study was to acquaint rural based medical and allied health professionals about the benefits of using palliative care in EOL treatment by starting a dialog through workshops and meetings.

### Methods:

1. Two communities in Hokkaido were selected for their relatively distant location from the prefectural capital of Sapporo.
2. Organised health service: a public health center in community A, a hospital established by a town in community B.
3. Conducted two 2 hour open workshops in two different contexts: a conference room and a cafe.
4. Distributed written questionnaires after the workshops and meetings

**Results:** The workshop held in a conference room, attracted 89 subjects in A and 43 in B. The workshop held in a cafe, attracted 37 practitioners in A and 38 in B. 85.9% participants from A answered the questionnaire while 100% of participants from B answered the questionnaire.

The majority of the participants were satisfied with the workshops. They stated that were willing to learn more about how to care for the terminally ill and their families. Over 80% of attendants requested more information and materials about EOL care using palliative care. Participants in both communities stated that communication between medical professionals and patients is a barrier in the caring of dying patients. Allied health professionals such as caregivers expressed an interest in palliative care training but time constraints do not allow them for additional training.

**Conclusion:** Palliative care was widely received by medical professionals and caregivers. More information and opportunities for medical professionals and allied health professionals interested in palliative care needs to be provided.

**Abstract number:** P2-288  
**Abstract type:** Poster

## Improving Quality of Living and Dying for People with Dementia Following the Gold Standards Framework Dementia Care Training Programme

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**Background:** The importance of End of Life Care for people with dementia is increasingly recognised. Evidence that people with dementia are at greater risk of inappropriate hospitalisation and interventions, and that hospital admissions can be detrimental with an increase in morbidity and mortality (double the non-dementia rate). In addition they suffer poorer quality of life sometimes during hospital admissions, due to severe disorientation, distress and anxiety, sometimes leading to behavioural issues, which are often a communication of their distress. In addition, care for people with dementia on a hospital ward poses particular problems for hospital staff, sometimes leading to inappropriate over use of psychotropic medication and sedatives. The Programme was supported by a DH grant.

### Aims:

1. Awareness of the impact on the person and their families and person-centred care.
2. Communication and Advance Care Planning with people with dementia.
3. Assessment and management of pain and distress in people with dementia.
4. Outcomes with more living and dying in their usual place of residence and reduced hospital admissions.

**Method:** Evaluation includes before and after measures, both quantitative and qualitative.  
**Result:** We report on the outcomes of about 100(MS1) learners in different settings and disciplines.

**Conclusion:** The programme shows improvements in staff confidence in caring for people with dementia towards the end of their life, and in the four key areas of improving outcomes, and has also shown that staff are able to better identify deterioration in a person with dementia as they approach the end of their life. The programme has proven to effect the whole organisation and all care homes staff, changing the ethos and attitudes within the organisation. This work is helping to put UK Government policy into practice.  
[MS1]Check numbers

**Abstract number:** P2-289  
**Abstract type:** Poster

## The Heart of Gold Projects – GSF Improving Area-wide Integrated Cross Boundary Care End of Life Care

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**Background:** In response to the growing challenges of the ageing populations and whole system area-wide end of life care one of the key factors is to develop an integrated cross boundary care approach to meet the needs of the population. GSF can be part of the solution in developing such integrated care by developing a common 'vocabulary' of care for all people in any setting with any condition in the final year or so of life. GSF is widely used in the UK in primary care, care homes, hospitals, domiciliary care and hospices. By working together to a common plan, GSF can help be a vehicle for improvement with patients at the heart of care, as 'gold patients' or VIPs, receiving gold standard care.

**Aim:** To use GSF programmes in different settings, to develop an integrated whole system

approach, with patients at the heart of care- the 'heart of gold' projects. GSF improves the early identification, Advance Care Planning discussions and coordination of care reducing unnecessary hospital admissions.

**Method:** The GSF Foundation Sites in Integrated Cross Boundary care include training in a number of settings, 'better together' workshops plus individual and collective evaluations. More detailed evaluations are developing such as the Delphi dashboard, plus practical and qualitative measures.

**Results:** Findings from the current areas are presented, showing the value of a synergistic approach in whole-system care.

**Conclusion:** Significant improvements are being seen across whole areas by using GSF as a vehicle for better coordinated care across different settings. 'Gold patients' and their families feel reassured that there is support available, and that they have a say in their care planning. Additional benefits include improved confidence of staff and pride in this area of work and 'cultural change' in care, especially for the frail elderly. Such a model is just developing in the UK, but early signs are encouraging.

**Abstract number:** P2-290  
**Abstract type:** Poster

## Palliative Medicine – From 2014 a 'Field of Competence' for Medical Specialists in Denmark

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**Background:** The Danish Association for Palliative Medicine (DSPaM) was established in 2001, and in 2003 we establish The Nordic Specialist Course in Palliative Medicine (NSCPM) in collaboration with our Nordic colleagues. The Danish Curriculum in Palliative Medicine (PM) was revised in 2013, when Palliative Medicine was classified as a 'Field of Competence' (FOC) in the national organisation for all medical associations (LVS). DSPaM has the responsibility for defining the theoretical and clinical demands for obtaining the title 'Field of Competence Specialist in Palliative Medicine' (FOCiPM), and for acknowledging the specialists. DSPaM has 145 members. Thirtyseven Danish doctors have passed the NCSPC to this date.

**Aim:** To describe the first application- and acknowledgement procedures and details about the physicians who applied and those who obtained the title FOCiPM in the first application round.

### Methods:

Demands for FOCiPM:  
Full specialist training in relevant specialty  
NSCPM or similar theoretical course in PM  
2 years of clinical work in specialist palliative care (as defined by DSPaM)  
Minimum 1 year with consultant colleague  
Minimum 1 year with in-patient care.  
The dead line for application was October 1<sup>st</sup> 2014

**Results:** 39 doctors applied in the first round, 16 men, 23 women. Mean age 56 years (range: 42 – 81). Specialties: Anaesthesiology 16, General Medicine 14, Oncology 4, Other 4, None 1. Theoretical course: NSCPM 24, Cardiff Diploma in PM 4, MSc in PC: 1. 24 doctors were acknowledged as FOCiPM, 3 had a conditional acknowledgement (insufficient clinical training), 11 were rejected, 1 was uncertain.

**Discussion:** The possibility to apply for FOCiPM continues in the 'transition phase', until we have a detailed training programme including a log book and classification of the specialist palliative care units in the training programme. In the future we hope to have time limited training positions in palliative medicine.

**Abstract number:** P2-291  
**Abstract type:** Poster

## Core Curriculum and Guidelines for the Basic Education of the Physiotherapist in Palliative Care, Published by Società Italiana di Cure Palliative

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The 'Società Italiana di Cure Palliative' (SICP) has published the Core Curriculum for Physiotherapists in Palliative Care (2013) to define the skills and educational requirements necessary for the consolidation and improvement of palliative care. It is a tool intended for decision-makers with the purpose of defining educational policies in accordance with the prime objectives proposed by the SICP.

The Guidelines for the Basic Education of Physiotherapists in Palliative Care, published by the SICP at the end of 2014, derives from the core curriculum and sets forth a specific educational program for providing appropriate knowledge in palliative care to students of the degree course in Physiotherapy.

Both documents are set out in tables that specify the effective nature of the skills and knowledge which are distinguished by the field of action:

- Ability to assess patients and their families
- Ability to relate to patients and their families
- Ability to take care of patients
- Ability to take care of patients and their families as a physiotherapist
- Ability to take care of families in various care settings
- Ability to work in a team
- Ability to coordinate a physiotherapy service
- Ability to deal with ethical and legal issues
- Ability to carry out research
- Ability to instruct

The knowledge and skills necessary for practicing physiotherapy in PC are extremely complex and regard various training contexts. It is required that an adequate education may be achieved through:

- The addition of specific studies to already existing educational programs
- The introduction of a specific course of Physiotherapy in Palliative Care
- The introduction of specific training.
- The importance of the content and the specific nature of the educational targets should stimulate appropriate reflection concerning the role and responsibilities of the trainers.



## Ethics

**Abstract number:** P2-292

**Abstract type:** Poster

### Motivations of Outpatients to Complete their Advance Directives

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**Context:** Despite the presence of advance directives (AD) in the health law in the Canton of Geneva for many years, the number of patients who completed their AD is low.

**Aims:** Identify factors influencing the writing of DA in outpatients. Describe the current involvement of medical and nursing staff in supporting patients to write AD.

**Methods:** One semi-structured questionnaire has been completed by outpatients that completed their AD and received home care. One other was completed by the nurse and the physician (GP) in charge of the patients at home.

**Results:** 74 patients of 1946 that received home care had completed AD. 34 accepted to participate and had no cognitive impairment. 7 patients were encouraged to fill AD by their GP, 4 by health professionals. 15 patients preferred to complete an existing questionnaire. 14 completed AD alone, mostly driven by their own motivation and they faced little difficulties. However 17 patients highlighted that more involvement of their GP would have been important. Main motivations of patients to complete AD were the onset of a severe disease with complications and the importance of not burden their relatives. Main cited items were: resuscitation, fear of suffering having his life extended. 18/21 nurses that completed the survey systematically asked the patients if they completed AD; 2 supported the patients to complete AD. 4/16 physicians that completed the survey systematically asked the patients if they completed AD.

**Conclusion / Discussion:** Motivations of the minority of patients that completed their AD are very individual. The completion of AD are seldom triggered by the health professionals in charge of them. To promote the completion of AD but we should be very creative and find other ways to promote shared decision making.

**Abstract number:** P2-293

**Abstract type:** Poster

### The Role of Emotion in the Process of a Good Death

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This paper articulates an Aristotelian approach to the correct role of emotions, in particular of fear, in the process of dying. An attempt to resolve the controversy that surrounds Aristotelian catharsis, results in the claim that it is a practical emotional therapy. The process of catharsis is dynamic: a process of emotional movement to cure emotional movement. In an endeavour to provide a plausible proposal for how emotions are to be balanced in the process of dying I argue that Aristotelian catharsis provides a good model for this, as it allows in a safe context for the expression of one's extreme fear of death and dying, which results in the allaying of this fear and the restoration of emotional health that allows for a peaceful death. Hence, Aristotle's cathartic process is one in which one is enabled to feel one's fear, in such a way as to thereafter lessen one's fear, and thereby come to feel it more appropriately. The greatest opposition to this Aristotelian approach is Stoicism about death. Whereas I take the challenge of dying well to involve achieving an appropriate balance of emotions like fear, the Stoics take the challenge to involve the eradication of fear through a rational education.

Nevertheless, narratives of dying taken from both factual and fictional literature demonstrate that a cathartic development of emotion is natural to the dying process. They also, however, provide cases in which the overwhelming fear of death prevented the person from dying well. Real case narratives reveal how psychotherapeutic techniques are used by medical practitioners in extreme cases to help relieve the emotional suffering of their patients so they can die well. And while these psychotherapeutic approaches do not describe the emotional process in cathartic terms, it is clear that what occurs is a cathartic development of emotion. A good death, therefore, involves an engagement with fear and not the extirpation of fear as the Stoics would have it.

**Abstract number:** P2-294

**Abstract type:** Poster

### Palliative Care and Quality of Life in the New Italian Code of Medical Ethics

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A brief analysis of the most significant provisions of the new Italian Code of medical ethics reveals the centrality of the ethical principles of beneficence, respect of autonomy, proportionality of care in the doctor – patient relationship.

In general, the application of these principles results in particular attention to promote the wellbeing and the quality of life of the patient, taken as a whole in his/her global dimension as a 'person'. This is explicitly stated in Section 3 of the Code according to which duties of the physician are the protection of life and psycho-physical health, the treatment of pain, and the relief of suffering, respecting the freedom and the dignity of the person.

The Authors therefore intend to analyse the new provisions of the Code, concerning the assistance to terminal patients and designed to establish specific rules of behavior, e.g. the avoidance of diagnostic procedures and therapeutic interventions not proportionate to the effective condition of the patient (Section 16), the prohibition of acts intended to cause the

patient's death (Section 17), the use of palliative care, pain sedation, and relief of suffering (Section 39). These provisions reflect a concept of protection of health which includes including all measures directed to achieve the best mental and physical balance in terminally ill patients, respectful of the dignity and therefore of the wishes freely expressed by the individual regarding his/her treatments (Section 38).

In assessing the moral significance of the very complex concept of quality of life, the Authors also intend to probe its direct bearings on the ethics of the healing practices and the medical profession.

**Abstract number:** P2-295

**Abstract type:** Poster

### Hospitalized Patients' Knowledge and Use of Advance Directives

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**Background:** Advance directives (AD) and the designation of a health care proxy are means for the patient to convey his care preferences in case he becomes incapacitated. Binding legal dispositions have existed for many years in canton Geneva. However these measures are useful only if the public knows about them and resorts to them.

**Objectives:**

1. Determine if a non selected population of patients addressed to a Pain and Palliative Care Consultation knows about AD and proxy.

2. Determine the proportion of these patients who have AD and/or a proxy.

**Methods:** All the patients hospitalised in the acute care hospital and the rehabilitation hospital of the University Hospitals of Geneva consecutively referred to the Pain and Palliative Care Consultation between January 15 and March 31, 2012 were included. They were asked closed questions about AD during a routine consultation.

**Results:** 51 patients were included. Half (n=25) were male. Mean age was 64.3 years (min 20, max 88). Thirty-five patients (68.6%) had a non oncological diagnosis. Half the patients (n=25) were hospitalised on a medical ward, and 16 (31.4%) on a surgical ward. AD were not discussed with 15 patients, mainly because of communication difficulties (decreased cognitive function, language). Ten patients (28%) knew or thought they knew what AD are, and 8 (22%) what a proxy is. Three patients had AD, 4 had designated a proxy, and 7 spontaneously mentioned a loved one who would act as a proxy. No cancer patient had AD or had designated a proxy.

**Conclusion:** A minority of patients knew about AD and a health care proxy. The public and the patients need to be better informed.

**Abstract number:** P2-296

**Abstract type:** Poster

### Advance Care Planning in a Psychogeriatric Unit at the End of Life

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**Background:** Dementia is the paradigm of increase in survival in chronic diseases through administration of treatments and medical techniques. Advance care planning (ACP) is an instrument that opens up areas of reflection between the patient and his/her representative in cases of incapacity, and the therapeutic team responsible for care. It enables implementation of adequate care and marks limits for cardiopulmonary resuscitation that could prolong the dying process in an inadequate way.

**Aim:** To assess the degree and type of ACP carried out in patients diagnosed with dementia who died in a Psychogeriatric Unit between January 2010 and July 2014.

**Method:** Descriptive, prospective study of demented patients who died in a Psychogeriatric Unit in whom ACP had been registered from January 2010 to 31<sup>st</sup> July 2014 through revision of medical histories.

**Results:** Six hundred and sixty patients were admitted to a Psychogeriatric Unit between January 2010 and 31<sup>st</sup> July 2014, 221 of whom died. Of the latter, 189 (85.5%) had ACP registered. Of this group of patients 95 (50.2%) were over 85 years old, 98 (51.85%) were females and only one patient had a living will. The most prevalent dementias were: 104 (55%) Alzheimer's Disease, 37 (19.57%) Vascular Dementia and 20 (10.58%) Lewy Body Dementia. Severity of the dementia was evaluated using the Global Deterioration Scale (GDS) which was registered in 151 (79.89%) of the patients with ACP. Of these, 91 (60.26%) had a GDS of 7 and 51 (33.77%) a GDS of 6. Do not resuscitate (DNR) orders were present in 109 patients (57.57%) and in 110 patients (58.2%) there were orders not to be admitted to the Intensive Care Unit in the event of medical complications.

**Conclusions:** ACP is registered in the majority of patients.

The most frequent types of ACP are DNR orders and do not admit to the ICU.

Patients with ACP have more advanced disease.

During the last 2 years there has been an increase in ACP registered in the case histories.

**Abstract number:** P2-297  
**Abstract type:** Poster

## Advanced Care Planning in an Acute Geriatric Unit

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**Background:** Advanced care planning (ACP) allows one to face the health problems of the elderly offering better care in accordance with their needs and preferences.  
**Aims:** To assess the prevalence, degree and type of ACP in patients admitted to our Acute Geriatric Unit (AGU) and describe the variables associated with ACP.  
**Methods:** Descriptive retrospective study of patients admitted to the AGU between May and June 2014 by revising the case histories.  
**Results:** During this period 188 patients were admitted to the AGU of whom 92 (48.9%) had ACP. Barthel Index prior to admission in the ACP group showed severe or complete dependence (Barthel < 35 or < 20) in 41 patients (45.1% of the ACP group), whilst there were 16 patients (16.6%) in the group without ACP, increasing on admission to 59 (64.9%) and 29 patients (30.2%) respectively. Dementia predominated in the group with ACP (37 patients: 19.7%) compared with 19 in the no ACP group (10.1%). With regard to identification prior to admission of patients with advanced chronic diseases and conditions in need of palliative care, no differences were detected between the two groups. On the other hand differences were present during hospital admission, 19 patients being identified *de novo* in the ACP group and 2 in the no ACP group.  
ACP was agreed with the patient in 11 cases (12%) and with the family in 66 cases (71.7%). In 12 (13%) intensive therapy on the ward was indicated. In 75 (81.5%) there were Do-Not-Resuscitate (DNR) orders in the event of cardiac arrest and in 76 (82.6%) orders not to be admitted to the Intensive Care Unit (ICU) in the event of medical complications. In 65 patients (70.7%) the decision was to prioritise comfort in the event of poor clinical course.  
**Conclusion:** ACP is registered in 50% of the patients in the AGU. Dementia and a low Barthel Index are present. ACP is usually agreed with the family. The most frequent ACP are DNR, do not admit de ICU and give priority to comfort.

**Abstract number:** P2-298  
**Abstract type:** Poster

## Ultimate Time of Life

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**Background:** When reaching the terminal stage of the cancerous disease, many patients ask the question about the time that remains to live: 'how long do you give me, doctor?'  
**Aim:** From these questioning, our reflection concerns this ultimate time: what about it? This time has questioned philosophers for a long time. So difficult to define, this limited time which separates these formulated questions and the death of the patient; an uncertain time for the patient, his family, the doctors and the nurses who accompany him. The High Authority of Health as well as the French Society of Accompaniment and Palliative Care insist that this time should not be neglected. What are the particularities for this temporality: nonsense of a life which cannot go on or greater value of every moment? How to live this time, alone, of course, but also surrounded by the nursing staff and close relatives whose course of life continues?  
**Method:** From these questions and having consulted the literature, we led fourteen semi-managed interviews with cancer patients in one palliative care unit. What about this time? Does the initial question (how long?), persist?  
**Results:** The qualitative analysis of the words allowed to better characterise this time. The patients also described the resources which allow to continue to live in such a process of mourning. This uncertain time is marked by heterogeneity: with sad words alternating with words describing a more serene real-life experience. Their life keeps a sense only if they are not suffering and are able to live in relationship with others. This time which tells itself the present, connected with a past and turned to a future!  
**Conclusion:** Obviously, this study does not erase the aporetic character of this ultimate temporality! But our work shows that the ultimate time is one of a new temporality which having no capacity to extend or to gain in length, would gain in 'width' or would dilate.

**Abstract number:** P2-299  
**Abstract type:** Poster

## Palliative Care Values

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The UK has a well-established Palliative Care service that grew out of the hospice movement of the 1950's. It is pioneering and evangelising, serving as a role model to other countries it seeks to spread an understanding of the needs of terminally ill people and their families. Historically, hospices took dying people out of mainstream healthcare to, as Cicely Saunders commented 'bring values back in'. Since the late 1980's Specialist Palliative care has attempted to take palliative care practices and values back into mainstream healthcare but as the recent criticisms of the application of the Liverpool Care Pathway (LCP) indicate; this has largely failed. This failure is significant for countries other than the UK, since many countries, Denmark included, have been seeking to follow the UK's lead. This paper draws upon the work of an earlier project, the first scrutiny of the ethics of palliative care in Europe, it also draws upon more recent bioethical research that is examining critically the values of palliative care within the UK and other European countries where hospice and palliative care are evolving. The method is empirically informed bioethics and draws upon expert testimony, conceptual analysis, official and media documents. The results indicate: Early critical commentary on the development of palliative care gave warning that palliative care would be under pressure from medicalisation, and from the managerialism that went hand in hand with mainstream health care. Mainstream health-care has a problem acknowledging death as a natural outcome and cannot agree upon the effective care for the dying person. Medicine continues to fail to deal humanely with dying people.

Care is at risk of becoming mere technique devoid of values. There is no consensus on the appropriateness of care across the illness trajectory.  
**Conclusion:** Now is an appropriate time to reflect upon the values which underpin palliative care.

**Abstract number:** P2-300  
**Abstract type:** Poster

## Narrative as a Contributing Factor in Solutions to Ethical Dilemmas of End-of-Life and Palliative Care

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**Background:** The unsolved ethical dilemmas can compromise the quality of end-of-life (EOL) care and cause moral distress in the healthcare team. Despite extensive theoretical reflection, guidelines and protocols, the ethical dilemmas continue to negatively affect patients and professionals as well as informal caregivers. The main problem might be that the most common approaches are proposed as purely logical procedures which, although rigorous in terms of methodology, fail to grasp the human good of the patient at the EOL. Abundant literature covers the many advantages of the narrative approach; however, until now, very little has been explored about how the narrative approach can contribute to the problem of ethical dilemmas in palliative care (PC) and EOL decision-making.  
**Aim:** To show how the narrative approach constitutes a useful, and even necessary tool, for the analysis and resolution of the ethical dilemmas that arise in EOL.  
**Methods:** Epistemological and moral analysis of the contribution of the patient's narrative to crucial dilemmas of PC. Three clinical scenarios are shown.  
**Results:** The scenarios will be on:  
a) refusal of treatments,  
b) palliative sedation, and  
c) goals of care.  
The patient's narrative does not consist in a mere sequence of events, but it captures the intelligible content of situations and expresses the moral/existential content of events which we observe on the external level. Therefore it should opportunistically integrate the most common methods of ethical dilemma analysis. Advance care planning (ACP) and shared decision-making (SDM) models partially assume a narrative approach and can take further advantage of a more explicit reference to the narrative approach.  
**Conclusions:** The logical and narrative knowledge are two complementary aspects of the ethical-clinical judgment. In a multidisciplinary team, the PC consultant plays a crucial role in facilitating the resolution of ethical dilemmas and fostering ACP and SDM models of care.

**Abstract number:** P2-301  
**Abstract type:** Poster

## 'Care Ethics' and Communication in Palliative Care: A Qualitative Study on Health Professionals' Perception of Ethical Issues

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**Aims:** 'Care ethics' is an ethical theory recognising subjectivity, the role of emotions and of interpersonal relationships in addressing moral choices. The key-concepts of this moral approach are: relational autonomy, dignity, vulnerability, shared truth, body perception, issues of meaning.  
The aim of this study was to explore the ethical issues in communication between health professionals and palliative care patients and their relatives, using the 'Care ethics' theory as a framework.  
**Methods:** The project includes three steps:  
1) a review of the literature on 'Care ethics' and its potential use for communication in Palliative Care;  
2) ethnographical observation of professionals working within a hospital palliative care unit and a hospice;  
3) semi-structured interviews to a sample of physicians and nurses working with patients with palliative care needs.  
Interviews, developed on the basis of the results of the previous steps, will be focused on how ethical issues are perceived and the way professionals deal with ethical dilemmas.  
**Results:** According to the results from the previous two steps, relational autonomy, the subjective meaning of 'truth', vulnerability and the role of emotions in moral choices were identified as core concepts to be explored within the interviews. Results from this study will represent the basis for developing an approach to communication and a model for communication teaching that takes into account the basic elements of this paradigm.

**Abstract number:** P2-302

**Abstract type:** Poster

## What Do Proxies Direct in Advance?

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**Background:** Advance directives by proxy (ADBP) – signed by the proxy, not the patient – are, although not a subject of the medico-ethico-legal discourse, a reality in German nursing homes: Two large studies demonstrated a prevalence between 12.4% and 25%. What do we know about form and content of ADBP?

**Methods:** The pooled ADBPs of two nursing home studies (n = 46) were analysed with regard to formal criteria, validity, and directions regarding life-sustaining treatments.

**Results** (preliminary analysis): The residents' age reached a median of 86 (range 50–101) years. The ADBPs were 1 (range 1–7) years old, 0.5 (0.25–4) pages long, and had been signed by 1 (0–5) persons. In 37%, the proxy's legal status was not clear; in only 2 ADBPs facilitation by a physician was documented. 85% were free texts (28% of which were entries in the nursing charts); 9% were regionally used forms. 63% contained information about the (justifying) foundation of the directives: earlier oral comments 30%, the impaired (17%) or suffering (15%) state of the resident, as judged by the proxy, or the resident's behaviour (11%). With 3 exceptions, the ADBP were confined to treatment exclusions, mostly for the case of complications arising from the actual (rather than a future hypothetical) state of health (any: 52%, cardiopulmonary resuscitation: 20%, hospital: 67%, tube feeding: 37%). In 28% of the AGDPs, palliative care was explicitly requested.

**Conclusion:** (German) ADBPs are mostly handwritten documents that typically regulate crises that may occur from the given state. The signee was often not recognisably legitimised, a physician's consultation was rarely documented, the ethical legitimisation of the ADBP was fragmentary and varied extremely. There is a great need for formal, content and ethical standards for ADBPs.

## Family and care givers

**Abstract number:** P2-303

**Abstract type:** Poster

## Functional Dependency of Patients at the End of Life and Overburdening of Caregivers: Cognitive State of Patient as a Modulator Variable

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Recent research point out that a high proportion of family caregivers of elderly patients at the end of life felt overburdened (Soto et al, 2014). Botella et al. (1998) define frail elderly as: a person that presents advanced age; some degree of disability; multiple chronic diseases; polypharmacy; geriatric symptoms; and high risk of hospitalisation, acute disease or death. Following this definition, the present study focuses in family caregivers of frail elderly at the end of life, studying the relationship between the functional dependency level of the frail elderly patients and the overburdening level of the family caregivers, taking into account the cognitive state of the frail elderly patients.

It is a cross-sectional study, in which participated 89 hospitalised frail elderly at the end of life, and their family main caregivers. Barthel Index, Pfeiffer's Short Portable Mental Status Questionnaire (SPMSQ), and Zarit Burden Interview were used.

A correlation between functional dependency levels of frail elderly at the end of life and the overburdening level of their main caregivers was found when patients presented a 'preserved' cognitive state ( $r = -0.315$ ;  $Sig = 0.048$ ;  $p < 0.05$ ). In frail elderly patients with a 'deteriorated cognitive state' and their family caregivers this correlation was not observed. Likewise, mean differences were found in the overburdening level of the family caregivers of frail elderly patients with different degrees of functional dependency, but only in the group of patients with a 'preserved' cognitive state.

According to the results from this study, it seems that the cognitive state of the frail elderly patients has a mediator effect between the patient's functional dependency level and the overburdening of their family caregivers. Further research is required, in order to clarify these relationships.

This study is founded by the Spanish Science and Innovation Department (PSI2010–19426).

**number:** P2-304

**Abstract type:** Poster

## How Is it Being a Parent to an Adult Child with a Seriously Ill Disease?

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**Background:** In Europe there are an ageing population structure and the cause is an increased life expectancy. This means that older person's likelihood will be confronted with their own family member's serious illness. Older parents are as a result of growing aged population at the risk that they may have to follow their adult child in a severe illness and even to their death.

**Aim:** A study to investigate how it is feeling being a parent to an adult child with a severe illness.

**Methods:** A qualitative design with mixed methods to gain a deeper understanding. It was done through qualitative data, collected by in-depth interviews and a questionnaire.

**Result:** The result showed that a common sense was that it is very special to have an adult child with a severe illness. There were five areas that was highlighted; The existential experience influence the conceptions of life and were underlying the whole situation. The other four areas which the parents show being important; It was Having information,

Participation, Strategies to cope with the situation and Support- including support for the parent and being support for the child.

**Conclusion:** Following an adult child with a severe and maybe fatal disease and with a growing elderly population this will be an increased problem. So far there are limited research in this area och the need for more research should be high priority.

**Abstract number:** P2-305

**Abstract type:** Poster

## Information to Family Members and Other Loved Ones – Being Updated Facilitates Involvement during the Hospital Stay/or during In-patient Palliative Care

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**Background:** A lot of research shows that information to loved ones is important. To ensure that the loved ones really are informed of the patients illness and treatment during the hospital stay the palliative care unit have started a project to evaluate how the information to loved ones can be improved.

**Aim:** To continuously inform the patient's loved ones about the progression of the illness and the daily treatment.

**Method:** The patient gives permission to the nurse that once a week give the loved ones information about recent treatment and planning. At a conference the team agrees on what information should be given. The nurse then contacts the loved ones, either when they visit the patient or by telephone.

The nurse fills in a questionnaire, like a diary, about the method's advantages and weaknesses.

**Result:** A pilot project has been started and the result so far is that the loved ones feel more involved in the patient's illness. Knowing what is going to happen and what is planned also make them feel safe.

**Abstract number:** P2-306

**Abstract type:** Poster

## For the Palliative Care Unit's Health Professionals, what Role to Play and how to Deal with the Patients in the Agonic Phase and their Close Family Members

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**Background and aims:** Agony is one period of the existence that is impossible to circumvent. The clinical signs have just been the object of a multicentric study by the national research's group whose name is 'Agony'. The professionals of Palliative Care Unit (PCU) are very often confronted with agony. Thus, the objectives of this study was to know what role to play and how to deal with the patients and their close family members, during this difficult period of the life.

**Methods:** This study was descriptive, multicentric and interprofessional. Preliminary semi-directed discussions were carried out. A protocol of validation was built with the assistance of two psychologists, eight doctors and eight caregivers of eight different PCU. In addition, an oral test was carried out.

This survey was conducted among the different professionals of 123 French PCU in April and May 2013, using a questionnaire of 19 closed or half-open questions.

The results were entered on excel and were studied statistically.

**Results:** 341 exploitable questionnaires were collected. The health professionals prove sensitised to taking care of the patient's body: analgesia (87%), body position 4 per day (48%), information et reassurance (80%), non verbal communication (77%).

They focussed on the importance to take into account the close family members and to listen to them regularly about pain (96%), prognosis (94%), nutrition/hydration (70%). Caregivers are mainly against euthanasia (82%).

Three guidelines come out from this study: comprehensive approach of the patient in agonic phase, listening in conjunction with 'therapeutic alliance', inter professionality as a support of the emotions.

**Conclusion:** These results make it possible to have a better knowledge of this significant and mysterious time which is agony. In the long term, this approach would aim at considering a harmonised specific training, improving the support of the health professionals.



**Abstract number:** P2-307  
**Abstract type:** Poster

## The Influence of Life Experiences with People at the End of Life on Attitudes towards Death and Dying

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**Background:** Relatives are usually expected to care of the dying family members. It provokes many emotions and difficult situations. There are many factors that can affect our attitudes towards caring for dying persons, such as previous experiences with people at the end of life.

**Aim:** The aim of this study was to collect data on relation between the experience of a relative's end-of-life in the past and attitudes towards death and dying at present.

**Methods:** Fifty four family members of deceased people participated in the study. Most of them was witness to the death of grandparents /40%/ or parents /39%/. 78% of respondents claimed that they took a direct part in caring for the dying close relatives. Self-constructed questionnaire containing 28 items related to the dimensions of the study has been used to examine any relationships between bereaved family members experiences and some factors that form said attitudes.

**Results:** Majority of respondents declared that if it was possible to turn back time they would have changed their behavior towards the dying one. However they were not sure whether they would care of terminally ill relative at home again. Faced with the idea of their own death respondents were afraid of leaving behind their family. They felt fear of dying rather than of death itself. There exist factors that impact mentioned attitudes, i.e. age, religiousness, the feeling of fulfilment, family support.

**Conclusions:** The previous experience of relative's death, as well as taking care of them shapes attitudes towards death and dying – both one's own and other people.

**Abstract number:** P2-308  
**Abstract type:** Poster

## Caregiver Coach Service: A Volunteer Service Aimed at Maintaining the Wellbeing of Family Caregivers

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**Background:** Family caregivers (FCGs) often experience decreased wellbeing while providing care and in bereavement. Clinicians often do not have time to focus on FCGs, leaving FCGs at risk for problems if their needs for support are not identified and attended to. Volunteers may have a role to play in supporting FCGs, but the literature indicates that they are not trained to focus on FCGs' own wellbeing.

**Aim:** To implement and formatively evaluate a volunteer service to coach FCGs of people at the end of life to maintain their own wellbeing in the patient's last months and in early bereavement.

**Methods:** Study design was informed by the participatory Fourth Generation Evaluation methodology (Guba and Lincoln 1989). Data were collected from FCGs (n=21), volunteers (n=13), their coordinator, and referring clinicians, as well as the service database, via various means, including interviews, reflective notes and time logs. Concurrent content analysis and descriptive statistics are being used for ongoing formative evaluation.

**Results:** The format of the Coach training program was revised: didactic presentations were eliminated and replaced by discussion of assigned reading and case studies. To date, all FCGs reported benefits from the service; several noted that they had difficulty envisioning benefits at the time of enrolment. The most common are: coaching to take care of their own wellbeing; speaking with someone with lay knowledge about their situation who is not a family member or health care provider; help finding community resources for patient care. Most FCGs appreciated a service looking out for them, but some would also like help with the patient. The Coaches and Coordinator report enjoying the project.

**Discussion:** Results so far suggest that the Caregiver Coach Service fills an important service gap for FCGs. A summative evaluation as well as a study to assess the pros and cons of solely focusing on the FCG vs also including patient care are warranted.

**Abstract number:** P2-309  
**Abstract type:** Poster

## Family Members Education at ASIH in Palliative Care

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**Background:** We were part of a study that was conducted in 2013 about family invention within home hospice care under the name 'Palliative care, active alleviation and support.' The objective of the study was to ascertain if education could make the family member feel more secure in the role as carer. Our experience as those who held the classes was that the family member did feel more secure and we wanted to continue the education and meetings for family members.

**Aims:** To give family members of palliative patients increased knowledge about palliative care, different strategies, including medical, spiritual and psychological, about the progression of disease, and how to care for patients. This to make them feel more secure in their role as a care giver of a palliative patient.

**Method:** Family members of patients with palliative diagnoses were invited to three meetings. At the first meeting a doctor talks about disease progression, medical treatment, useful strategies when the end is near and about the process of dying. At the second

meeting a nurse talks about the way life changes, how to make daily life easier through strategies such as closeness, nutrition, hygiene and adaptive equipment. At the third meeting a counselor talks about normal psychological defenses, the family's relationships and how the home hospice counselor can help. Every meeting started and ended with a nurse to help create group togetherness, to lead discussion and end with a relaxation technique. An evaluation was given to the participants at the last meeting to be able to improve the meetings.

**Results:** The evaluations show that the family members were satisfied with the meetings, that they had a better understanding and that it was supportive to meet other family members in the same situation.

**Conclusion:** We saw that the family members has gained greater sense of security, a greater knowledge and a better understanding of what services we in home hospice care offer.

**Abstract number:** P2-310  
**Abstract type:** Poster

## Is Primary Caregivers' Satisfaction with Home Palliative Care of Patients with Cancer Associated with Caregiving Outcomes?

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**Background:** The caregivers' satisfaction consists an important quality of palliative care indicator.

The aim of this study was to describe the primary caregivers' satisfaction with home palliative care of patients with cancer and to explore the association of their satisfaction with caregiving outcomes.

**Methods:** The study took place at the only Palliative Care service providing home care to adult cancer patients in Greece. Eighty two (N=82) primary caregivers of newly – admitted patients, during the 2<sup>nd</sup> to 3<sup>rd</sup> week of care completed

a) a demographic and clinical form,

b) the Famcare Scale, a 20 five-point Likert type items instrument divided into 4 subscales (Information, Availability of care, Psychosocial, and Physical patient care),

c) the Bakas Caregiving Outcomes Scale.

**Results:** Most of the caregivers were females (74.7%), their mean age was 55±15.5 years old and were patient's spouses (42.7%). The patients' mean age was 68.6±17.5 years old, and their mean Palliative Performance Status was 46.7±18.3 (0–100). The caregivers reported a high satisfaction with the home palliative care of patients' (Mean Total (4.7±0.4) and Psychosocial (4.8±0.4), Information (4.7±0.4), Availability of Care (4.6±0.3), and Physical Care (4.6±0.4) subscales satisfaction scores). Additionally, the caregivers reported good adaptational caregiving outcomes (58.0±15.8 (15–105) that were not associated with total satisfaction (rho=–0.09, p=0.411, N=82) and subscales scores (p>0.070). Moreover the Multiple Linear Regression Analysis revealed that none of the examined patients' and caregivers' demographic and clinical characteristics was recognised as an independent factor of caregivers' satisfaction.

**Conclusion:** This study is the first exploring the satisfaction of caregivers with home palliative care of cancer patients in Greece. Despite that caregivers were very satisfied with patients' care, further investigation is needed to explore other factors associated with their satisfaction.

**Abstract number:** P2-311  
**Abstract type:** Poster

## Handling of Relatives with Psychiatric Diseases on a Palliative Care Unit – Experience of the Nurses

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**Aim:** Relatives with psychiatric diseases are a challenge for Palliative Care teams. Since the patients are seriously ill and therefore they might loose their partner, the relatives are frequently also in a crisis. Furthermore, the relatives are not in their familiar environment and the physicians who normally control the psychiatric disease don't have frequent access to their patients. The nursing staff of Palliative Care units has frequently no experience in the care of relatives with psychiatric diseases.

**Methods:** We have used a non-standardised interview to evaluate the difficulties and challenges the interaction with relatives who suffer from a psychiatric disease causes for the nurses.

**Results:** Eight nurses participated in the interviews. All described that the care for relatives with psychiatric diseases has been experienced as a severe crisis for the Palliative Care team, especially the nurses. As a severe burden have been identified the missing knowledge of the disease and the disturbed behavior, especially during night time. Furthermore, being responsible not only for the patient but for the relative has been described as a challenge, especially, if medication for the relatives has been in need because of a psychiatric crisis.

**Conclusion:** There is a high burden for nurses caring for relatives with psychiatric diseases on a Palliative Care unit. Especially during night time when access to physicians might be limited, the burden increases. Based upon these experiences we will develop systematic strategies for the handling of relatives with psychiatric diseases on a Palliative Care unit.



**Abstract number:** P2-312  
**Abstract type:** Poster

## The Design & Dignity Project. Transforming End of Life Care in Hospitals, one Room at a Time

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**Aim:** To describe the outputs of the Design & Dignity Project. Phase 1 The goal of the Design & Dignity Project is to transform the way hospital spaces are designed for people at the end of life and their families by awarding over €1.5m in capital grants to hospitals in Ireland.

**Approach:** Public hospitals in Ireland were invited to submit applications for grants to renovate areas used in end of life and bereavement care. Hospitals were supported with architectural advice from the awarding body during the application stage. Qualitative and quantitative data submitted by hospitals was analysed by the awarding body.

**Results:** 11 hospitals were awarded grants for the renovation of family rooms, mortuaries, gardens and bereavement suites in emergency departments. Before and after photographs powerfully illustrate the positive improvement made to the physical environment. National and international media coverage was secured to demonstrate the value of the project. A freely-available style book for hospital staff and architects was developed based on learning from phase 1. Further funding for the Design & Dignity Project was secured and phase 2 of the project was initiated in 2014.

**Lessons learned:** Through the Design & Dignity Project cluttered rooms and dreary facilities are transformed into tranquil spaces where families gather to be with each other and their deceased family member. Testimonies from hospital staff, patients and families illustrate the enormous impact the renovated spaces have on their end of life and bereavement journey. Learning from phase 1 informed modifications to phase 2. This included a revised application process to increase the qualitative and quantitative data submitted by hospitals to the awarding body. An increased level of architectural support was made available to hospitals during the phase 2 grant application stage. Design guidelines based on evidence from phase 1 have been adopted by the main national health care provider.

**Abstract number:** P2-313  
**Abstract type:** Poster

## Palliative Care Needs of Family Carers: A Literature Review

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**Aim:** The aim of this piece of work was to establish, from the literature, the current situation for family carers providing care to a dying loved one and provide some direction for working with them.

**Design:** A review of the literature was carried out by searching key terms on the databases CINAHL and PubMed, searching academic journals and non-academic grey literature websites. 121 Articles retrieved were assessed for relevance and information was synthesised by identifying prominent themes. The themes to emerge are: 'General Support', 'Psychological Distress', and 'Decision Making'.

**Results:** The literature indicates the following:

1. Family carers providing end of life care are often undervalued and underrepresented in the literature.
2. Family carers require support in the form of information, respite care and financial assistance.
3. Family carers experience high amounts of isolation and are found to experience significant losses upon death of their loved one and/or on transition to a continuing care setting.
4. Clarity around the decision making processes at the end of life is required, and the extent of responsibility family members have in this area.
5. Family carers were found to enjoy the caring role and when adequately supported experienced more positive bereavement outcomes.

**Conclusion:** Although the palliative care approach addresses the needs of family carers as well as the person with life limiting disease, the needs of the carer are not routinely acknowledged. Health care agencies need to provide greater direction and support to family carers so that they can fulfil their caring role with confidence, this will be done with the development of a leaflet for family carers caring for a loved one at the end of life and learning modules that family carers can access.

**Abstract number:** P2-314  
**Abstract type:** Poster

## How Do Terminally Ill Patients Facing Death Experience Comfort? A Differentiated Understanding of their Network

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**Background:** Studies exploring close network of terminally ill patients have primarily focused on perspectives of relatives. How do terminally ill patients experience relationship to his or her relatives? Empirical knowledge is scarce on how comfort of relatives can strengthen dignity and identity of patients.

**Aim:** To acquire a differentiated understanding of how and to which extent comfort from terminally ill patients' network support them in their effort to manage life and changes brought by disease.

**Method:** A qualitative study was conducted with individual in-depth interviews with six terminally ill cancer patients. The interviews were based on patients' life stories to obtain a more detailed insight into the subject. Following Kvale and Brinkmann's theory of analysis interviews were transcribed, coded and main themes were extracted.

**Results:** The study showed that terminally ill patients experience three different types of comfort: 'The active comfort' supports terminally ill patient's identity through social activities as close to patient's values and lifestyle as possible. 'The passive comfort' is a phenomenon where relatives giving comfort take on the role of a co-sufferer feeling sorry for the patient and displays an attitude characterised by sentimentality and clinging. 'The third form' of comfort as a drive is the kind of comfort patients get from fellow patients. In this situation the personal problem is transformed into a universal problem as it is not unique but general to

the entire group. This kind of comfort has a supportive identity-creating effect similar to 'active comfort'.

**Conclusion:** This qualitative study comprising interviews with six terminally ill patients showed that they experienced three different types of comfort: 'active comfort', 'passive comfort' and 'comfort as a drive'. The results emphasise an individual approach to comfort and more knowledge is needed on how professionals can support the interaction between the patient and the relatives.

**Abstract number:** P2-315  
**Abstract type:** Poster

## Teenagers Reasoning about their Parent's Recent Death

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**Background:** Teenagers are greatly influenced by a parent's illness and death.

**Aim:** To explore how teenagers reason about their parent's recent death and their life without the parent.

**Methods:** The study has a descriptive-interpretive design using qualitative content analysis. Ten teenagers (14–19 years), seven boys and three girls, participated through repeated interviews that were carried out as free conversations.

**Results:** Importantly, all teenagers appreciated to participate in the interviews. It was somewhat painful to be reminded but still a great relief to talk about the death of the parent and their own life without the parent. Some of them had not earlier talked more in depth about this to anyone while others had open communications in their families. All teenagers showed up for a second interview indicating a wish for continued conversation. Most of them talked in detail about the days around and the exact day and hour of their parent's death. All expressed a wish to be included and present despite their own sorrow and feelings of helplessness when watching their parent suffer from pain or other symptoms. Some of them considered the hard part to be over after the parent's death while others considered the opposite. Unselfishly, they felt that death had relieved the parent from suffer and a life with severe illness. They seemed to at least partly have adapted to a life without the parent, expressing life is back on track, and mostly they could look forward in life. It was very important to remain a teenager living an ordinary life in school with friends.

**Conclusion:** Teenagers want to be included and present around the time of their parent's death. All teenagers in the study appreciated the chance to talk about their parent's illness and death and many had never talk about it before. Adults in their social network as well as health professionals should take on the responsibility and initiate conversations with teenagers during these traumatic life events.

**Abstract number:** P2-316  
**Abstract type:** Poster

## Using a Self Completed Checklist to Assess and Manage the Needs of the Carers of People with Advanced Cancer in General Practice: A Randomised Controlled Trial

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**Aims:** The carers of patients with advanced cancer have specific health and psychosocial needs, often not addressed. We assessed whether GPs could meet these needs if they are self-assessed by the carer.

**Methods:** Prospective randomised controlled trial. Intervention was a self-reported checklist completed by the carer followed by a carer-GP consultation, at baseline and at three months; and b) a GP-Toolkit to assist GPs to provide relevant interventions to address carer-identified needs. We also identified how needs change over time in all carers, and what needs were expressed over time in intervention carers.

**Results:** N=392. No significant differences were detected between groups in either the number or intensity of needs. Compared with controls, participants with baseline clinical anxiety showed improved mental wellbeing (p= 0.027), and those with baseline clinical depression developed anxiety more slowly (p=0.044). Physical wellbeing improved for people not anxious at baseline (p=0.040). Those caring for patients with AKPS >=60 had improved mental wellbeing (p= 0.022), but carers of people with AKPS < 60 had more physical needs (p=0.037) and more psychological and emotional needs (p=0.034) compared to controls. Hospital parking, impacts on working and other activities and balancing personal and patient needs remained highest needs over time. Making decisions about the future, and concern over cancer coming back became more important with time.

**Conclusions:** This intervention did not influence the number or intensity of needs reported by carers of people with advanced cancer. The intervention had limited positive effects in people with pre-existing clinical anxiety and depression. It reduced physical needs in people who did not have clinical anxiety. It had negative effects on people caring for the people most severely affected by advanced cancer, possibly by drawing attention to the significant impacts of caring for such severely ill individuals.

**Abstract number:** P2-317

**Abstract type:** Poster

## Effects and Meanings for Patients when their Family Caregiver Participate in a Psycho-Educational Intervention during Ongoing Palliative Care

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**Background:** Patients receiving palliative care often have great need for support and practical assistance from their family members who becomes central in providing the care. Studies show that family members feel more prepared, competent and rewarded in relation to their caregiver role when receiving sufficient support. However it is not known whether and how this actually affects their care of the patients.

**Aim:** To explore effects and meanings for patients when their family caregiver participate in a psycho-educational intervention during ongoing palliative care.

**Method:** An interpretive descriptive design was chosen and qualitative interviews were conducted with eleven patients whose family members had participated in a psycho-educational intervention. All the patients received specialised palliative homecare. The interviews were analysed with qualitative content analysis.

**Results:** Most patients expressed thoughts about being a burden to their family members and therefore felt relieved by their participation in the intervention. To all patients it was of importance that their family member was supported and had someone to talk with about their feelings and the situation. They felt reassured that their family members were given an opportunity to increase their possibilities to handle the difficult situation. None of the patients disapproved of the family members participation and they didn't worry concerning what was said about their process of illness or anything about their situation. Patients sensed that their family member were more prepared and with a different approach at home that could be due to increased insights and knowledge, even if no effects on the actual care were seen.

**Conclusion:** Patients did benefit from the intervention and felt relieved as their family members got supported and a chance to prepare for the situation. Nevertheless, they couldn't see any effects on the actual care in their present situation.

**Abstract number:** P2-318

**Abstract type:** Poster

## Elaboration of a Psychosocial Attention Manual for Caregivers of Patients with Palliative Needs

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**Introduction:** It is essential to take care of oneself, in order properly take care of others. When an advanced disease affects a person, the consequences go far beyond that person, affecting the whole family. Then, it is invaluable to have the right tools to properly manage the situation.

**Objectives:** Our goal is to provide a guide for the caregiver that will increase awareness of the importance of self-caring. We want to shine a humanistic and encouraging point of view of what is taking care for a patient who is a close relative, through the experience of professionals and with the important help of caregivers who wanted to collaborate with their testimonies to provide a realistic point of view to this work.

**Methodology:** A bibliographical review of psychosocial care for patients with palliative needs was carried out. We have verified the necessity of developing a manual to provide caregivers guidelines, tools and strategies for dealing with various scenarios that happen during the care of a person having an advance disease. We counted on the testimonies of caregivers so that their real emotions and experiences are expressed.

**Results:** After checking out the current bibliography and the day-to-day care we have verified that caregivers that are aware of self-caring are more suitable and experience less emotional breakdown.

**Conclusions:** This manual will serve as a tool capable of representing the psychosocial needs of caregivers and families with patients with advanced disease. It will provide the adequate resources to facilitate their psychosocial and emotional wellbeing. The first edition has 3000 copies.

**Abstract number:** P2-319

**Abstract type:** Poster

## Self-care Practice Ability Program: Practical Program for Caregivers in Palliative Care

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Variables of well-being and exhaustion are generally related to family caregivers in palliative care (PC). Few studies which focus specifically on interventions aimed at their treatment – a practical preventive interventions to enhance the internal/external resources of the patients and families.

To create a program named Self-care Practice Ability Program (SPA Program) to increase the well-being and reduce exhaustion of the caregivers by combining skills training and complementary therapies. The SPA Program had 3 six-hour modules (Practical; Emotional; and Relational), unfolded in 4 steps, in a period of 3 months:

- 1 – the participants (\*P) signed the informed consent and filled out a scale to identify the module to be addressed by the team;
- 2 – \*P filled out the Zarit scale and the Personal Wellbeing Index;
- 3 – \*P responded a satisfaction questionnaire;
- 4 – Repetition of step 1 and 2.

Criteria: oncologic PC caregivers; ≥ 18 years; verbal and writing comprehension of Portuguese language.

In 2013 a PC Service (in Oporto) treated 641 patients, 85% of whom had an oncologic diagnosis (follow up median=17 days). The \*P who addressed the Practical module (N=4)

had registered a positive value at the end of the sessions. Five \*P who worked the Emotional module, 4 had increased their capability in this field. In the Relational module only 2 out of 5 \*P concluded the program. However, this dimension registered positive values in the other groups, despite not having addressed this theme directly. 7/11 \*P presented exhaustion prior the start of the program; at the end these levels had decreased significantly. We conclude that \*P levels of well-being increased at the end of the SPA program. The number of \*P is a limitation which may be related to the oncologic prognosis of the patients that continue to arrive too late to PC treatment thus affecting the family empowerment. Therefore we propose that this type of program should focus mainly on non-oncologic patient's caregivers.

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**Abstract type:** Poster

## Sleep among Bereaved Caregivers of Patients Admitted to Hospice: A 1-year Longitudinal Pilot Study

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**Background and aims:** Caring for a dying family member is known to interfere with sleep, yet little is known about bereaved caregivers. This pilot study aimed to describe the sleep of partners and other family caregivers during the first year after a hospice patient's death.

**Methods:** The pilot study used a longitudinal, descriptive, comparative design. Participants included primary family caregivers of patients admitted to a hospice in Norway. Caregiver sleep was measured subjectively with the Pittsburgh Sleep Quality Index (PSQI) and objectively using wrist actigraphy for 3 days and nights at three different times: during the hospice stay, and at 6 and 12 months after the patient's death.

**Results:** Sixteen family caregivers (10 partners and 6 other family members) completed the 1-year study protocol without difficulty. Overall, sleep quality and quantity were stable over time, and at each assessment, approximately half of the sample had poor sleep quality, both by self-report and objective measures. However, the sleep trajectories differed significantly over time, with older caregivers (>65 years) having significantly longer sleep durations than younger caregivers (< 65 years). Furthermore, sleep quality also differed over time depending on the caregiver's relationship to the patient, with partner caregivers having significantly worse sleep quality than other family caregivers over time.

**Conclusion:** Findings demonstrate feasibility of the longitudinal study protocol and indicate that sleep problems are common for caregivers and continue into the bereavement period, particularly for partner caregivers. The caregiver's relationship to the patient may be an important factor to consider in future studies.

**Source of funding:** The study was supported by Lovisenberg Diakonale University College and Lovisenberg Diakonale Hospital.

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## Team Support for Parents with Cancer who Have Young Children

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**Background and aim:** Parents who are diagnosed cancer have much psychological distress and several problems for family, especially children. Palliative care teams support for patients, their partner and children. We always have conference with primary medical staff before patients' support. We report support and needs of parents with cancer who have young children through consultation to our team.

**Methods:** We study retrospectively medical electronic records of support by palliative care team for patients who have young children (under 20 years) about patients' demography, support needs, interviews and activities.

**Results:** 60 patients (m/f 27/33, ave.43yo) requested to our team from April 2013 to October 2014. Average age of children (108) was 9. Support was offered by a certified nurse and a hospital play staff of our team. Eleven patients were supported with their partner and 22 cases were application from partners. Eleven cases needed to support children directly. Parents' major concern was how to tell about parent's diagnosis to their children including poor prognosis. One case was requested as bereavement care for children just after the parent died. Primary nurses also have worry about patients' distress and needed advices from our team about family support.

**Conclusion:** A certified nurse and a hospital play staff offer support for cancer patients who have young children. It should be realised one of important supports in oncology. Further study should needed to effective support by team to reduce their distress.

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## Care Competence and Caregiving: A Profile of Caregivers Supporting Advanced Cancer Patients Receiving Home-based Palliative Care

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**Background:** Diagnosis of cancer has a significant impact not only on patient, but also on their caregivers. In Italy more or less 92% family caregivers are often responsible for providing support to advanced cancer patients. However, evidence suggests that caregivers receive limited information and help to support them for such a role.

**Aim:** The aim of this study was to identify which family caregivers' characteristics could be associated with a better competence in taking care of end-of-life home cancer patients.

**Methods:** A structured interview measuring caregiver's competence in giving basic and specific care and in communicating patients' needs to health professionals, was administered to a sample of 166 caregivers caring for advanced cancer patients who were assisted by a palliative home care team. The differences between categorical variables were analysed with chi-square tests and Fisher's exact tests.

**Results:** 149 family caregivers (89,8%) were able to provide basic care, 131 (78,9%) specific care and 140 (84,3%) were able to communicate patients' needs to health professionals. Older caregivers seemed to have more difficulties in providing specific care no matter their degree of kinship ( $p = .008$ ). Caregivers with lower education tended to have lower communication competence ( $p = .02$ ). Therefore, significant correlations were found between competence in reporting patients' needs and competence in providing basic care ( $p < .001$ ) or competence in providing specific care ( $p < .001$ ).

**Conclusion:** These results show that older caregivers should require a more intensive support in order to provide a more accurate and complete care to advanced cancer patients. Moreover, health professionals should acquire a set of knowledge and skills to improve communication with caregivers having a different social and cultural background.

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**Abstract type:** Poster

## Exploring Carers' Experiences of Supporting a Person with Palliative Heart Failure: A Mixed Methods Study

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**Aims:** This paper presents preliminary findings and methodological challenges of conducting a study exploring the impact of being an informal carer for a person with palliative heart failure on carer quality of life and factors influential to carers' perceptions of caring.

**Method:** The study is a 2 phase sequential mixed methods study. A sample of carers was recruited from Heart Failure Nurses (HFNS) caseloads in UK rural and urban settings. Carers were invited to complete the Family Quality of Life (FAMQOL) questionnaire, a tool developed for carers of heart failure patients. Participants were also asked to provide contact details if they are willing to be interviewed.

**Analysis:** Questionnaire data was entered onto SPSS and analysed for correlations between variables. Interviews were analysed using Interpretive Phenomenological Analysis which recognises the centrality of the researcher in exploring and interpreting the participants' beliefs and descriptive dialogues of being a carer.

**Results:** 120 questionnaires were distributed to HFNS, each nurse being given 20 questionnaires. A third of carers who returned the completed questionnaires agreed to participate in an interview. Initial response rate was good but questionnaire returns gradually decreased over a few weeks. It transpired that due to the nature of the service delivery, on average each nurse distributed 5 questionnaires during a three month period. The author of the FAMQOL tool reported similar issues in the USA when using HFNS as gate keepers to carers.

**Conclusion:** The study highlights important methodological considerations for recruiting carers. As the intention was to begin the analysis of the questionnaires prior to commencing the second phase of the study, the researcher was compelled to consider how integration was maintained and how to improve access to carers for research. Reflections and recommendations addressing these methodological challenges will be critically discussed in the paper.

## International developments

**Abstract number:** P2-324

**Abstract type:** Poster

## Palliative Care in Egypt: The Experience of the Gharbiah Cancer Society

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**Background and context:** The need for palliative care in middle and low resources countries, including Egypt, is emerging. The Gharbiah Cancer Society (GCS) is a nonprofit, nongovernmental hospital, located in Tanta, the Capital of the Gharbiah governorate in the mid-Nile Delta. The Society provides acute care to patients with cancer including surgery, chemo-, and radiotherapy. Review of nine year-data of Gharbiah population-based cancer registry from 1999 to 2007 revealed 3480 cancer cases/year, with Age Standardised Rate (ASR) of 161.7/100,000 for males & 120.8/100,000 for females.

**Aim:** About 70 % of cases present in advanced stages (III&IV) with liver cancer the most frequent cancer in male and breast cancer as the most frequent cancer in females. The GCS started a comprehensive palliative care services in April 2011 with 10-bed inpatient unit and six days/week outpatient clinic. All palliative care equipment were provided by public donations.

**Strategy/Tactics:** Through collaboration with Cancer Institute in USA, a fellowship training program was developed for a medical oncologist in palliative medicine and End-of-Life Care training course for nurses.

**Programme/Policy process:**

The program succeeded in convincing local health authorities to increase the recommended opioids dose and to allow more physicians to prescribe opioids for cancer pain. In a period of 24 months, symptom management and palliative care were provided to 195 patients with advanced malignancies. The opioids consumption was increased by 30 folds.

**Outcomes/what was learned:** The Major challenges for the program were inadequate public and health professionals awareness of palliative care services and lack of vehicles and finances to cover home visits. The initial results of the program warrant allocating more resources for coverage of a large number of trainees and instituting a home visits program.

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**Abstract type:** Poster

## The Importance of Continuing Medical Education (CME) in the Diffusion and Adoption of Best Practice Palliative Care Protocols in Six Northern European Countries (non-empirical)

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**Aims:** Continuing Medical Education (CME) has been touted as an important means for propagating best practice protocols for palliative care in the physician population, but there is little research on this important assumption. This study aims to assess the impact CME training – or lack of CME training — has had on palliative care in six northern European countries: Denmark, Finland, Norway, Sweden, Great Britain, and Germany.

**Research design:** Analysis will involve a comprehensive review of the literature on (1) CME policy and practice and (2) the sophistication of palliative care provision in the selected countries.

**Results:** It is too soon to report results as work on this study is still in progress.

**Conclusions:** Conclusions will be drawn about the impact CME education has had on palliative care provision, with an eye toward making recommendations about how much and what kind of palliative care CME might be indicated to bring all countries (those in the study and even others) up to standard in this important area of medicine.

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Abstract type: Poster

### International Palliative Care Network Conference: Free Participation and Access

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**Aims or goal of the work:** To promote the free exchange of knowledge amongst palliative care professionals across the globe.

**Design, methods and approach taken:** An annual online conference is hosted on the Palliative Care Network (PCN) community website. A theme decided by an international planning committee leads to experts in the field being invited to present lectures. In addition, abstracts are invited to be submitted for both lectures and a poster exhibition. All disciplines are included and awards are sponsored for the poster exhibition by various organisations and a publication. All materials are prepared on power point to ensure easy participation and access. The conference enjoys the endorsement of various organisations internationally and has been held under the auspices of the European Association of Palliative Care.

**Results:** The International Palliative Care Network Conference (IPCNC) hosts the works of palliative care professionals from across the globe and enables the free exchange of knowledge. Based on feedback, this has led to changes in perceptions, knowledge base, policies and practices across the globe. Some of the feedback received is:

'This will improve teaching of the medical students as the information has improved my knowledge very much' Africa

'The lecture series on the models has allowed me to reframe the current work I am doing on a statewide model of care.' Australia

'I had no prior experience in hospice and palliative care. I was very impressed. I will more quickly identify patients I can refer for PC consults.' USA

'We can study the trend of palliative care in the world.' Japan

**Conclusion / lessons learned:** IPCNC is an effective avenue for the exchange of information amongst palliative care professionals across the globe. This is a no cost and high impact initiative for participants.

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### Preliminary Findings from the Stakeholder Advisory Panel Meetings with Experts and Families in a Project Health Technology Assessment – INTEGRATE in Poland

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**Introduction:** The aim of the HTA-INTEGRATE project is to find the best model of palliative care using stakeholder advisory panels (SAPs) in several European countries involving experts and patients from the palliative care field.

**Methods:** Two SAPs panels were held in Poland including experts and patient families. Meeting involved at least 8 participants in each group. Meeting were organised in September 2013 and in June 2014. Each meeting took 3 h. Two moderators led the discussion.

**Results:** The meetings were highly appreciated by both experts and families as it was possible to discuss all important issues in views of participants that were important for Polish situation in palliative care. Several problems were identified by both experts and families. Experts indicated insufficient funding from the National Health Fund for palliative care and especially inadequate allocation of existing resources. Families identified several weaknesses and strengths of palliative care services. Among weaknesses families indicated problems in communication with medical staff, limited availability in case of emergencies, limited availability of palliative care in rural areas, gaps in education of families that care for patients at home. Among strengths the surveyed listed good quality of palliative care services, medical and psychosocial support, availability of rehabilitation at home.

**Conclusions:** Using the HTA-INTEGRATE SAPs meetings allowed to identify several strengths and limitations of palliative care in Poland. It may serve as a base for the improvement in organisation, resources allocation and quality of care for palliative care services in Poland.

HTA – INTEGRATE project is supported from the EU

## Medical sociology

Abstract number: P2-328  
Abstract type: Poster

### Dying in Prison: A New Form of Shameful Death

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**Aims or goal of the work:** In the last decade the number of older men in prisons, in both the UK and many European countries, has increased sharply, leading to a rise in anticipated deaths in prison. This paper draws together sociological scholarship around contemporary dying and the rapid growth in prison populations with early scoping work from the 'Both sides of the fence' study of prison dying, to propose that dying in prison is an important new form of shameful death.

**Design, methods and approach taken:** Increases in the prison population have been theorised by Wacquant as flowing from political change, and correlate with the extent to which countries have embraced neoliberalism. In its simplest form, neoliberalism is a set of ideas associated with economic policies aimed at reducing government spending and enhancing the role of the private sector. Locating recent change in prison dying within Wacquant's theoretical framework and using data from discussions with staff providing palliative care in prisons, we theorised that aspects of neoliberalism shape prison dying. We then explored the damaging and protective mechanisms involved.

**Results:** Neoliberal prison policies have multiple implications for prison dying, one of which is the new shameful death. In prison death, shame attaches to the person as well as to place, raising questions about practical and discursive resources available to protect the self at the end of life. Reductions in prison resources consistent with such policies compound the indignities of prison dying.

**Conclusion:** The nature of these population and policy shifts mean challenges for prison staff as well as having consequences for prisoners. Staff draw on universalist discourses underpinned by ethical practices, which serve to protect both staff and prisoners. However, political and policy decisions shaped by neoliberalism threaten further resource reductions and undermine protective discourses, so impact negatively on prison dying.

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Abstract type: Poster

### Impact of 'Life before Death' Movie in Raising Awareness for Palliative Care

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**Background:** The concept of palliative care (PC) is not well understood in Romania as proves a population study where the terms 'hospice' and 'palliative care' were correctly defined by less than 5% of the respondents. In same study visual media was rated by over 2/3 as the main channel for information.

**Aims:** To assess the usefulness of 'Life Before Death' movie as an information tool for PC for the general public and the medical students.

**Method:** Experimental study with pre / post intervention assessment. Intervention: 'Life before Death' movie applied on two self selected samples: one from the general population (GenP), one from medical students (MS) in Oradea. Before and after the intervention participants had to fill in a questionnaire with 11 questions concerning their definition of PC, services, beneficiaries, potential PC interventions, preferred place of care, etc.

**Results:** Out of the 112 GenP attending 87 completed both pre post questionnaires (RR=77,67%) and 84 MS out of the 98 (RR=85,71%). The length of the movie was a problem. 2 GenP and 7 MS could initially define palliative care and after the intervention 64% GenP and 78% MS gave the complete definition; all were able to present pain&symptom management, team work as part of PC. Initial low awareness regarding the types PC services, after intervention differences between the groups in understanding the concept of self standing hospices (better for GenP) and outpatient and hospital PC teams (better for MS); over 70% in both groups preferred end of life care at home. The intervention had no impact in wish for aggressive treatments at end of life and alternative medicine both being seen as part of good PC.

**Conclusion:** The movie was an effective intervention in explaining what palliative care is, in increasing awareness on home care and in patient PC services, not so good for PC services in other locations and not enough to challenge some preconceptions concerning treatments at end of life.



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**Abstract type:** Poster

## Reasons for, Appropriateness and Avoidability of End-of-Life Hospital Admissions: Results of a Survey among Family Physicians

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**Background:** The acute hospital setting is considered not to be an ideal place for final care or as a place of death. However, many patients are being admitted to an acute hospital setting at the end of life and die there subsequently.

**Aims:** To examine the reasons for end-of-life hospital admissions, whether they are considered appropriate or avoidable and what made them appropriate or could have avoided them as according to the family physician (FP).

**Methods:** A retrospective survey was used among FPs concerning the last hospital admission of their patients that died on an acute ward of university hospital in Belgium (January 2014 to August 2014). Only patients that died non-suddenly were included in the analysis. Descriptive analysis was used.

**Results:** 233 completed questionnaires were received (response rate 65.1%); of those 76.7% died non-suddenly (N=178). The most frequent medical reason necessitating the end-of-life hospital admission was treatment for a specific symptom, while other non-medical factors were also considered to have influenced the decision whether or not to admit (e.g. family was convinced that care was better in the hospital). Only 12 (7.0% of all cases) were considered to be avoidable according to the FP, while 84.9% was appropriate. Medical reasons were most frequently reported as the most important reason that made the admission appropriate and 52.2% of all potentially avoidable end-of-life hospital admissions could have been avoided by informing the patient earlier about his/her life expectancy or by providing more adequate support to family caregivers.

**Conclusions:** Only a minority of all end-of-life hospital admissions were considered to be 'inappropriate' or 'avoidable' according to family physicians. This might indicate that the acute hospital setting might be the most adequate setting at the end of life in these circumstances and that the potential to actually avoid them may be limited in the present Belgian health care system.

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**Abstract type:** Poster

## Staff's Understandings of Cross-cultural Interaction in End-of-Life Care: A Focus Group Study

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**Background:** There is evidence of poorer quality of health care among people from ethnic minorities in the context of end-of-life care (EOLC). Even though staff members' understandings of cross-cultural interactions may influence the individual's and the team's actual care of dying patients from ethnic minorities and their families, there is relatively scarce knowledge about this.

**Aims:** To explore staff members' understandings of cross-cultural interactions from the perspective of EOLC.

**Methods:** Sixty health care professionals were recruited from eleven health care units that provided EOLC. The focus group interviews were analysed using qualitative content analysis.

**Results:** Staff expressed concern about their ability to provide equal EOLC to people with ethno-cultural backgrounds that are different from their own. Differences in ways of handling the EOLC process were talked about in terms of the challenges they pose: communication, emotional expressions and pain, families/relatives, and knowledge. The informants expressed that it was vital that they as care professionals have knowledge about ethno-cultural minorities, and also about how to communicate with patients and families who have such backgrounds. The staff members' understandings also conveyed that cross-cultural interactions bring about uncertainty, stress, feelings of not doing a good job and being mistrusted in their professional role. When the staff discussed the identified challenges, they tended to focus on patients with ethnic minority backgrounds irrespective of their specific ethno-cultural backgrounds, and to compare those patients with patients of the ethnic majority. Limited experience of cross-cultural interactions did not hinder staff to have understandings of such meetings.

**Conclusion:** Important aspects of staff's understandings of cross-cultural interaction during EOLC were identified, which have implications for clinical practice and the need of a process perspective in future research.

**Abstract number:** P2-332

**Abstract type:** Poster

## Applying Health Promotion Methodology to Reach out to Populations Habitually Unaware of Palliative Care

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**Background:** Large proportions of European populations have complex needs and yet, they are unaware of the possibility of receiving highly skilled responses to these needs. Health Promotion approaches can promote changes to facilitate social progression by educating people.

**Aim:** To apply Health Promotion divulgative methodology to extend PC philosophy, know-how, knowledge and understanding.

To work at municipal level to achieve much needed social penetration of the PC concepts.

**Approach:** Working closely with local Health, Health Promotion and Social professionals to organise workshops and informative talks, we identified areas of interest, potential work and further developments. Initially, general chats of the history of PC and developments were offered, followed by question and answer sessions. From these, more focused sessions were organised. Particularly significant was the request to move the programme to a distant Nursing Home, distant from main stream Health facilities. The successful afternoon came from a well attended event including professionals, residents and a large group of relatives who came in specially.

**Results:** Analysis of social impact measured three years later in terms of PC activity in the area, home and nursing home deaths. Trends identified in the sessions were closely related to those commonly associated with Health Promotion: leadership, empowerment and communication.

**Discussion and conclusion:** This initiative has changed the End of Life experience, interest and professional courses and debates in this locality. We intend to extend it to other areas as it is very cost-effective and has an important impact on social understanding of PC philosophy. End of Life Care could change substantially supported by a Health Promotion approach.

## Health services research

**Abstract number:** P2-333

**Abstract type:** Poster

## Inequality in Admittance to Specialised Palliative Care (SPC) of Referred Cancer Patients? A Study from the Danish Palliative Care Database (DPD)

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**Background:** Few previous studies of admittance to specialised palliative care (SPC) have taken the actual need for SPC into account. Physicians refer patients they judge have a need for SPC. To be admitted to SPC the referral must be judged relevant by the SPC unit. However, not all referred and relevant patients are actually admitted to SPC.

**Aims:** Among adult cancer patients referred to SPC to investigate whether the likelihood of admittance was related to sex, age, diagnosis, geographic region, referral unit or year of death.

**Methods:** Using the Danish Palliative Care Database, all adult cancer patients referred to SPC who were deemed eligible by a SPC unit, and who died in 2010–12 were identified ( $n = 21,474$ ). Associations between the explanatory variables (sex, age, diagnosis, geographic region, referral unit, year of death) and the outcome variable admittance to SPC were investigated using logistic regression analysis.

**Results:** The overall admittance proportion was 83 %. A sex difference was found with higher odds of admittance to SPC for women (OR=1.16; 1.07–1.26). The admittance decreased strongly with increasing age. The odds of admittance to SPC were over five times higher for the youngest (18–40 years old) compared to the 80+ years old (OR = 5.38; 3.21–9.00). Patients with non-Hodgkin lymphoma (OR=0.56; 0.37–0.83) and leukemia (OR=0.55; 0.41–0.73) had the lowest odds of admittance to SPC. A difference in admittance was found based on geography, with the lowest odds of admittance in the Capital Region of Denmark and Region of Southern Denmark.

**Conclusion / Discussion:** In this first nationwide study of admittance among patients referred to and eligible for SPC, we found an inequality in admittance to SPC in Denmark, disfavoring older patients, patients with haematological malignancies and those living in two of the five Danish geographic regions.

**Abstract number:** P2-334  
**Abstract type:** Poster

## Research Priority Setting in Palliative and End of Life Care: The James Lind Alliance Approach Consulting Patients, Carers and Clinicians

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**Background:** There can be a mismatch between what the public (including professionals) see as important unanswered questions and those questions which are actually researched. This project aimed to help research funding bodies target limited funds to areas most relevant to palliative care populations. The Palliative and end of life care Priority Setting Partnership (PeolCSP), facilitated by the James Lind Alliance (JLA), sought to identify and prioritise questions about palliative and end of life care that people in the last years of life, current/bereaved carers and professionals working with people at the end of life feel are important for research to address.

**Methods:** A UK public survey (December 2013 to April 2014) identified questions about the support, care and treatment of people in the last years of life. From the responses, research questions were generated and are being prioritised by a second survey and, using the Nominal Group Technique, a workshop in November 2014.

**Interim results:** 1403 surveys were returned. Most respondents identified as bereaved family members/friends and health or social care professionals. Respondents submitted questions on a range of conditions and topics; including services, treatments, support, communication, symptoms and perceptions of palliative care. From the responses, 83 research questions were generated and using the JLA protocol the top 10 evidence uncertainties will be reported in January 2015. Responses that are 'out of scope' of the JLA protocol will be analysed and reported separately.

**Conclusions:** The top 10 uncertainties will guide the funding strategies of project partners and other funders, ensuring that future research is more relevant to palliative care populations. The process has challenges. Although difficult it must be ensured that patients', carers' and professionals' views are represented throughout. Research priority setting methods are evolving; it is hoped our experience can help future projects.

**Abstract number:** P2-335  
**Abstract type:** Poster

## Italian Palliative Care Services: The Role of Patients' and Professionals' Views in Health Technology Assessment Scope Development

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**Background:** Palliative care services are growing, but vary across Europe. Palliative care is being used as a case study to test the methodology developed within the INTEGRATE-HTA project. The project aims to develop methods to enable an integrated assessment of complex technologies such as palliative care. The engagement of stakeholders in Health Technology Assessment (HTA) is widely recommended as it ensures that a large number of perspectives have a voice and due consideration.

**Aims:** To identify stakeholder views of the key issues impacting on palliative care to facilitate the HTA project scope development. The present work focuses on the findings from participants in Italy.

**Design:** 'Patient' (n=7) and professional (n=8) stakeholders were enrolled as participants in qualitative research. Semi-structured interviews, lasting approximately 45 minutes, were either conducted face-to-face or over the telephone. An adapted version of the EUneHTA core model, which guides HTA development, supported the interviews. Responses were audio recorded and transcribed into a synopsis presentation. Thematic analysis identified key issues.

**Results:** Respondents identified similar issues including: access to palliative care services above all for non-cancer populations; availability of palliative care throughout the country; availability of home palliative care services; communication with patients and family members; improvement of quality of life in patients; staff education; training; implementation of legislation regulating palliative care.

**Conclusions:** Interviewing persons with experience of palliative care allowed us to identify important topics and to assist the INTEGRATE-HTA project scope development. This engagement will ensure that perspectives of patients, families, carers, professionals will have due consideration within the HTA process.

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**Abstract number:** P2-336  
**Abstract type:** Poster

## Trends and Characteristics of Inpatient Palliative Care for Cancer Patients in Taiwan from 2000 to 2010: A Nationwide Study

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**Background:** Inpatient palliative care (IPC) is the main stream of hospice care in Taiwan, however, the trends of IPC and patient characteristics of IPC have not been well explored.

**Aims:** To investigate the trends of IPC and characteristics of patients receiving IPC in Taiwan 2000 to 2010.

**Methods:** This study was a secondary data analysis by analysing the National Health Insurance Database (NHIRD) comprising anonymised secondary data from patient registries and claims data of the Taiwan NHI Program. We identified subjects diagnosed with the leading cancers, including hepatic, lung, colorectal, gastric, female breast, cervical, oral, and esophageal cancer by ICD9-CM code in the registry of catastrophic illness. Patients with multiple cancers were excluded. Income levels, residence urbanisation, comorbidities, hospitals levels and teaching status of the hospitals were identified. Compound annual growth rates (CAGR) and trends of IPC, and patient characteristics were presented. Descriptive statistics were presented.

**Results:** Total 44,232 patients had IPC, the majority of patients were male (59.1%), and the mean age of cancer diagnosis was 62.86 ± 14.53 years and that for the first IPC was 64.58 ± 14.24 years. Majority of the patients had a middle income (45.4%), lived in the urban area (60.5%), hospitalised in teaching hospitals (65.4%) and regional hospitals (46.2%). The total CAGR of IPC was 15%, and the CAGR in non-teaching and teaching hospitals were 34.6% and 13.3%, respectively. The CAGR of IPC in tertiary, regional and local hospitals were 13.4%, 17.4%, and 25.0%. The trends of IPC for different hospital teaching status, and hospital accreditation levels were significantly different (P < 0.0001).

**Conclusion:** There were increasing trends of IPC in Taiwan during 2000 to 2010, and different patient characteristics, including age at cancer diagnosis, income level, residence urbanisation and different hospital characteristics of IPC were noticed.

**Abstract number:** P2-337  
**Abstract type:** Poster

## The Ability of Advanced Cancer Patients to Attend an Outpatient Palliative Medicine Clinic to Collect Opioid Analgesics in Egypt

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**Background:** Cancer pain control in Egypt is largely inadequate because of the unavailability of opioids and the restrictive regulations that limit accessibility. Fear of misuse is still a barrier to dispensing opioids for cancer pain in Egypt. As a result of the fear of misuse, it is not an uncommon practice to request the physical presence of patients with advanced cancer to dispense opioid analgesics.

**Aim:** To estimate the proportion of advanced cancer patients who can not attend regularly an Egyptian outpatient palliative medicine clinic (PMC) to collect opioid analgesics.

**Methods:** Attendees of the PMC were asked to rate the difficulty of attending the PMC regularly by the patient to collect opioid analgesics.

**Results:** Fifty-six consecutive attendees (33 patients and 23 informal caregivers) of the PMC were included. For the whole group, the difficulty of the patient to attend the PMC regularly to collect opioids was rated as none by 18 (32%) attendees, mild by 3 (5%), moderate by 11 (20%) and severe by 24 (43%). The reasons of difficulty reported by the attendees were: difficult mobility in 23 patients (41%), difficult transportation in 7 (13%), financial reason in 4 (7%), pain in 2 (4%), hospitalisation in 1 (2%) and social reason in 1 (3%). Caregiver attendees were more likely to rate the difficulty of regular attendance by the patient as moderate/severe (p=0.009). Among the studied variables, the only one associated significantly with moderate/severe difficulty was an Eastern Cooperative Oncology Group performance status of 3-4 (p< 0.001).

**Conclusion / Discussion:** Attending an Egyptian outpatient PMC regularly to collect opioid analgesics is difficult for the majority of advanced cancer patients. The physical presence of advanced cancer patients in the clinic should not be a prerequisite to dispense opioid analgesics. Finding alternative ways to assess patients, like home visits, would save terminally-ill cancer patients unnecessary suffering at the end-of-life.

**Abstract number:** P2-338  
**Abstract type:** Poster

## Implementing Advance Care Planning Across a Healthcare System: Identifying Local Barriers and Facilitators

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**Background:** Advance Care Planning (ACP) is a process of reflection and communication of a person's future healthcare preferences. Promulgation of ACP is a priority for many healthcare systems. However, how to prospectively identify potential local barriers to uptake of ACP across a complex multi-sector healthcare system and develop specific mitigating strategies, is not well understood.

**Aims:** To understand local barriers and facilitators to the uptake of ACP across the publicly funded provincial healthcare system in Alberta, Canada, and to identify mitigation strategies relative to the local context.

**Methods:** We surveyed Alberta Strategic Clinical Networks (SCNs)—teams tasked with implementing transformational innovation in healthcare. The survey was based on published literature on barriers and facilitators to ACP and on the Michie Theoretical Domains Framework to address changes in healthcare provider behavior in the uptake of best practices.

**Results:** Fifty-one of 88 SCN members (58%) completed the survey. 'Insufficient public

engagement/understanding', 'conflict among different provincial health service initiatives', and 'lack of infrastructure' were identified as the most important local barriers. From a health practitioner point of view, 'lack of time to engage patients', and 'inadequate electronic reporting systems' were identified as significant barriers. 'Mastery of the skills needed', and 'emotional discomfort with initiating the ACP/GCD process' were also highlighted. These barriers were then explored through a semi-structured interview with key informants, who identified mitigating approaches.

**Conclusion:** Identifying and addressing local barriers to the uptake of innovation has been described as a core element of successful knowledge translation. Identifying and addressing local barriers to ACP uptake and identifying mitigating strategies through discussion with key informants was successfully undertaken through a brief survey and group discussion.

**Abstract number:** P2-339

**Abstract type:** Poster

## Evaluation of the Efficacy of Psychosocial Teams' Intervention: A Randomized, Open, Controlled, Multi-centred Phase III Study

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**Background:** The Program for the Comprehensive Care of Persons with Advanced Diseases from 'la Caixa' Foundation (PCCPAD-CF) has implemented psychosocial teams that offer support in regards to emotional, spiritual and social issues and contribute to patients' integral care.

**Aims:** To evaluate the efficacy of the psychosocial teams' intervention on levels of emotional distress in people with advanced disease and emotional distress as measured by the Detection of Emotional Distress (DED) scale, being moderate (DED $\geq$ 9) or severe (DED $\geq$ 13).

**Methods:** A randomised, open, controlled, multi-centred, phase III study. 80 subjects (candidates to be taken care by the PCCPAD-CF, being  $\geq$  18 years old and giving informed consent) are randomised in a 1:1 ratio to Arm A: psychosocial intervention every 3 days (days +2 and +6) during a period of 7 days in combination with conventional intervention or Arm B: conventional intervention.

Psychosocial intervention consists of addressing patient's emotional distress through psychotherapeutic techniques depending on each patient's needs. Conventional intervention consists of non-specific psychosocial intervention offered by healthcare professionals. DED scale is administered to all enrolled subjects at days +2 and +6. Method of statistical analysis: Primary efficacy endpoint is the proportion of subjects with DED $<$  9 at 7 days after completed intervention. Test Z for two proportions will be used to determine if hypothetical difference between population proportions differs significantly from that observed in the samples. An interim analysis of data will occur when reached half the planned recruitment (40 subjects).

**Results:** Recruitment is currently ongoing (11.2% completed by October 2014). Results from the interim analysis are expected to be available in June 2015.

**Conclusion/discussion:** A study to evaluate efficacy of psychosocial teams' intervention within PCCPAD-CF has been designed and implemented.

**Abstract number:** P2-340

**Abstract type:** Poster

## The Cost of Palliative Care in Breast, Colorectal and Prostate Cancer

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**Aims:** To explore the resource use and cost of palliative treatment among breast (BCa), colorectal (CRC) and prostate cancer (PCa) patients.

**Methods:** Patients in palliative care were recruited from the Helsinki University Hospital's Department of Oncology and from a local hospice (Terhokoti). Resource use, demographics and cost data at 2010 price level were extracted from a wide range of registers, and a self-administered questionnaire. Costs were divided into 1) direct health care costs (HCC), i.e., medication and in- and out-patient costs, 2) productivity costs, i.e., the value of days absent from work due to cancer, and 3) informal care costs, i.e., care given free by family or friends. Time dependency of HCC was explored by dividing them into two-week periods in the last 12 weeks of life.

**Results:** Of the 70 palliative care patients 43 (61%) were males, the median age was 70 (range 35–87), 13 had BCa, 33 had CRC, and 24 had PCa. The mean duration of palliative treatment was 179 days: 59 in BCa, 181 in CRC, and 239 in PCa, respectively. The last two weeks of life contributed 27% of the total HCC. The costs of palliative care were higher in patients living alone (Table). This was especially true for inpatient care (11013 vs. 4879 euro, p=0.018).

	Informal care	Productivity cost	Direct health care cost	Total cost
Cohabiting	5341(31)	2414(14)	9614(54)	17369(100)
Non-cohabiting	7657(23)	7664(23)	17642(55)	32963(100)
All patients	6136(27)	4216(19)	12370(54)	22722(100)

[Mean cost of palliative care in euros (%)]

**Conclusions:** Costs of palliative care are substantial but only a relatively small proportion of the costs is caused by direct health care resource utilisation. These costs are highest during the last two weeks of life. Living alone is clearly associated with higher costs and more inpatient days. Therefore, more support should be arranged for patients living alone to enable end-of-life care at home.

**Abstract number:** P2-341

**Abstract type:** Poster

## Because Trust and Justice Matter: Perceptions of Health Professionals Providing Palliative Care in Primary Care Services

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**Background:** Organisations' true sustainable advantage is its people. Health professionals are key-players in providing quality patient-centred care. Their perceptions of the structure and processes of the workplace may affect their performance and quality of care. Trust and procedural justice are core features in healthcare organisations. Studying these variables is relevant to evaluate micro, meso and macro outcomes in health services research and evaluation.

**Aims:** To analyse the relationship between two organisational contextual factors (trust and procedural justice) and psychological empowerment among professionals providing generalist palliative care in primary care settings.

**Methods:** As part of a larger multicenter survey study, a random sample of 209 professionals (nurses and physicians) providing primary palliative care in two Spanish regions was drawn. Three pre-validated scales were used to measure trust, procedural justice and professional empowerment: The Trustworthiness, the Procedural Fairness and the Psychological Empowerment Questionnaires. Multiple regression analyses were performed to study the hypothesis of trust and procedural justice being positively associated with psychological empowerment.

**Results:** As hypothesised, both trust ( $\beta=.164$ ,  $p<.05$ ) and procedural justice ( $\beta=.229$ ,  $p<.01$ ) in the workplace were significantly and positively associated with perceptions of psychological empowerment in health professionals from primary palliative home care services.

**Conclusions:** Based on these findings, recommendations can be made to ensure that healthcare managers and professionals leading primary care teams facilitate the implementation and delivery of palliative care by promoting trustworthiness and fairness in their teams. These are critical to create conditions (trust within teams and fairness of formal decision-making policies) that facilitate teamwork and promote empowerment in primary care settings, contributing to the quality of care provided.

**Abstract number:** P2-342

**Abstract type:** Poster

## Burnout in Palliative and Intensive Care Units: Does it Make a Difference?

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**Background:** Repeated contact with dying and death is a major burnout risk factor. Hence, professionals working in palliative and intensive care are at special risk.

**Aims:** To identify and compare burnout levels and its related factors among professionals working in palliative and intensive care units in Portugal.

**Methods:** Multicenter quantitative, comparative study. The Maslach Burnout Inventory was used for data collection together with a questionnaire of socio-demographic and profession-related variables, and a questionnaire of work-related experiences in the week and day prior to completion. 392 professionals participated in this study; 92 worked in palliative care units (PCUs) and 300 in intensive care units (ICUs). Univariate and multivariate logistic regression analyses were performed; OR sidelong with 95% of CI were calculated.

**Results:** While 25% of the professionals working in ICUs exhibited burnout, only 3% of those working in PCUs exhibited this syndrome. Univariate logistic regression analysis showed that burnout was inversely associated with working in PCUs (OR= .419; .224–.785 95%CI). When controlling for other variables (e.g., professionals' socio-demographic characteristics, post-graduated education in intensive/palliative care, work-related experiences), differences remained significant (OR= .396; .161–.976 95%CI). Higher levels of burnout in ICUs were related to being a nurse (OR=1.849, 95%CI 1.029–3.321) and experiencing conflicts (OR=2.170 95%CI 1.218–3.866).

**Conclusions:** Burnout is inversely associated to working in PCUs. Work-related experiences (e.g., conflicts in the work context) increase the risk of developing burnout among professionals providing end-of-life care. These findings suggest the need to further implement conflict-management strategies in these settings, helping professionals to cope with high-demanding situations associated to providing end-of-life care.

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**Abstract number:** P2-343  
**Abstract type:** Poster

## Empowering Leader Behaviours: Impact on Health Professionals' Empowerment and Commitment

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**Background:** The importance of leaders' behaviours in empowering staff in the workplace is advocated in healthcare management literature. However, there is a lack of empirical evidence linking empowering leadership behaviours with professionals' sense of workplace empowerment and commitment. Facilitative leadership styles are considered important to redesigning work in palliative care provided in primary care services.

**Aims:** To test a model linking leader-empowering behaviours to health professionals' perceptions of workplace empowerment and commitment in primary care.

**Methods:** As part of a larger multicenter survey study, a random sample of 209 professionals (nurses and physicians) providing palliative care in primary care settings in two Spanish regions was drawn. Three pre-validated scales were used to measure leader-empowering behaviours, empowerment and commitment. Multiple regression analyses were conducted to test the mediation model.

**Results:** Overall, perceptions of workplace empowerment were significantly related to all dimensions of leader-empowering behaviours. These dimensions were correlated with empowerment and commitment ( $r_s = .31$  to  $.63$ ). Empowerment at least partially mediated the relationship between leader-empowering behaviours and commitment. Empowerment had a significant impact on commitment ( $\beta = .64$ ,  $p < .05$ ).

**Conclusions:** The results of this study highlight the importance of facilitative leaders in creating empowering work environments. Hence, recommendations can be made to ensure that healthcare managers leading primary care teams facilitate the implementation and delivery of palliative care in these settings by promoting professionals' empowerment and commitment. This study provides encouraging empirical support and guidance for healthcare leaders interested in creating highly-effective work environments that benefit both patients and professionals who care for them within current turbulent healthcare organisations.

**Abstract number:** P2-344  
**Abstract type:** Poster

## The Organizational Landscape of Generalist Palliative Care in Danish Hospital Departments

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**Background:** In Denmark, 48% of all deaths take place in hospitals. Many die from chronic progressive diseases, often preceded by frequent hospital stays. Obviously, the need for palliative care (PC) should be addressed in the patients' encounter with the hospital system, as a routine in the daily clinical work. If, and how, the departments have organised their provision of PC, is by large unknown.

**Aims:** To examine Danish hospital departments' organisation and focus on PC.

**Methods:** A survey was sent to managers of the 410 hospital departments in Denmark, who treat patients. The survey addressed whether PC was prioritised and implemented at the organisational level in the departments (depts).

**Results:** A total of 318 (78%) depts responded, 85% had palliative patients among their clientele, 73% could provide PC if indicated, and 64% had focus on PC. Among medical (N=80), surgical (N=95), psychiatric (N=40) and childrens' (N=14) depts, 93%, 77%, 43% and 71% could provide PC, respectively. Half of the depts would refer palliative patients to specialist PC to a greater or lesser extent (32% answered 'always or often'), 33% of the depts had a policy for PC, 17% had allocated resources to PC, and 11% had used the specialised PC teams to increase the staffs' palliative skills. Whether the depts had guidelines for PC, was only known by 35% of the respondents.

**Conclusion / Discussion:** The majority of managers of hospital depts confirmed they had a focus on PC. However, focus did not seem to equal a policy or organisation of PC in the depts as recommended by the health authorities and the hospitals' national accreditation procedure. This survey has pinpointed some areas to address in the depts' provision of PC; e.g. sparse allocation of resources, unawareness of guidelines and scant use of specialist PC teams to improve the staffs' PC skills. It is imperative to know the depts' awareness towards PC and organisation of PC if general PC in the hospitals shall be promoted and improved.

**Abstract number:** P2-345  
**Abstract type:** Poster

## Is Emergency Department Attendance Associated with Factors Relating to Preferences for Place of Death? A Population-based Mortality Followback Survey

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**Background:** Emergency Department (ED) use is considered an indicator of poor quality end-of-life care and increases the risk of dying in hospital but it is unclear whether this reflects patient preference.

**Aims:** To examine the association between factors related to preferences for Place of Death (PoD) with ED attendance by cancer patients in the last 3 months of life.

**Methods:** Population-based mortality followback survey with 596 bereaved relatives of adults who died of cancer (QUALY-CARE study, London 2009–10, response rate 39.3%). 582 responses and corresponding death registration data were analysed using bivariate analysis to compare patients who attended the ED to those that did not in terms of hospital stay and death, and factors relating to preferences for PoD.

**Results:** 56% of patients visited the ED once or more in the last 3 months of life (median 1, range 1 to 8 visits). ED attenders were more often admitted to hospital (93.8% vs. 52.7%,  $p < 0.001$ ), were hospitalised for longer (median 14 vs. 0 days,  $p < 0.001$ ) and more often experienced a hospital death (37.1% vs. 19.5%,  $p < 0.001$ ). Moreover, ED attenders were less likely to have discussed their preference for PoD with family (54.8% vs. 66.5%,  $p = 0.005$ ) or health professionals (50.4% vs. 65.5%,  $p = 0.002$ ). Their preference for hospital death was no different from those who did not attend ED (5.7% vs. 3.9%,  $p = 0.482$ ). The most common preference was to die at home (69.2% ED attenders, 67.8% non-attenders).

**Conclusions:** We found that ED attendance by terminal cancer patients is common (more than 1 in 2 experience this) and associates with increased hospital stay and hospital death. This has cost implications as health systems struggle with funding and ED closures. Our results also suggest that ED attendance may reflect poorer planning and patient choice for PoD. This prompts policy and practice to improve community palliative care and facilitate discussion of preferences.

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## National Perspectives on Dying and Bereavement – Ireland 2004 and 2014

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**Background:** Policy/service developments benefit from being planned relative to people's views – their current opinion & future concerns. Over the last decade international and Irish surveys have engaged with the public about end of life.

**Aims:** This study aims to examine the contemporary knowledge, attitudes and behaviour of Irish people with respect to death and bereavement. Comparisons with baseline data from 2004 & UK data will be made.

**Method:** A questionnaire was designed based on Irish and UK surveys. Research ethics approval for a survey process was obtained. Adults from the republic of Ireland were randomly sampled to participate in an omnibus telephone survey. A telephone survey was conducted with a representative sample (n=891) during May 2014.

**Analysis:** Frequencies & descriptive statistics were generated; comparison by region, gender, age and class was conducted.

**Results:** 57% felt there was not enough discussion about death & dying (up from 51%). Dying at home was the preference of 74% (up from 67%) & most do not believe their preference will be available for them (53% up from 45% in 2004).

More than half (53%) experienced the death of someone close in the previous two years & 26% of these deaths were at home. Wishes for end-of-life were consistent with 2004 & with international surveys – to be surrounded by people you love, and free from pain.

Nevertheless, most (two thirds) have not given others direction on their preference or written advance plans. Organ donation and writing a will are the exceptions. Suicide and accidental death were thought to be in the top three causes of death by 47% and 35%. In fact these causes account for only 5% of deaths in Ireland annually.

**Conclusion:** There is appetite for discussion but still limited action around end of life plans though over half have been recently bereaved. Preferences are more strongly stated than in 2004. These trends will be discussed relative to changes in Ireland between 2004 & 14.

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## The Orkdal Model: Establishment of an Integrated Oncology and Palliative Care Outpatient Clinic to Improve Collaboration and Care – Who Are the Patients?

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**Background:** Integration of palliative care into oncology may improve quality of life for patients and family members, increase patients' time spent at home, and reduce aggressive end-of-life treatment. An integrated outpatient cancer clinic was established at a local hospital (Orkdal) in Mid-Norway in 2012.

**Aims:** The Orkdal Model aims to develop, implement and evaluate an integrated model of palliative cancer care. It consists of a standardised care pathway coordinating care within specialist- and community care, and between the two levels; an educational programme for healthcare providers; and information on palliative care to patients, their family, and the general public. The present study aimed for describing the patient population.

**Methods:** All patients visiting the Orkdal outpatient cancer clinic from October 2013 to July 2014 were eligible. Data regarding socio-demographics, cancer disease and subjective symptoms were collected by the EAPC Basic Dataset. Numerical rating scales from 0 to 10 were used for symptom assessment.

**Results:** 119 patients participated. Mean age was 67. Fifty-one percent were females. Stage of disease was: metastatic 62%, locally advanced 14% and local 19%. The three most prevalent cancer diagnoses were prostate (21%), breast (19%) and colon (15%). Treatment intention was: curative 30% and palliative 66%. Mean Karnofsky performance status was 84%. 101 patients had more than one registration. 31 patients died in the study period; among these 33% died at home. Mean intensity scores were: pain 1.86, depression 1.30 and well-being 2.46.

**Conclusion:** An integrated model to improve palliative cancer care is developed. Data from patients, family members and healthcare providers will be collected prospectively and compared with the present data and with a control population. The model may be applied in other regions and for other chronic diseases.

**Funders:** The Central Norway Regional Health Authority and the Norwegian Directorate of Health.



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**Abstract type:** Poster

## Focus-groups with Family Practitioners (FP) on How to Deliver High Quality Palliative Care (PC)

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**Background:** Palliative care (PC) is a rewarding but difficult task for each family practitioner (FP). The Care Pathway for Primary Palliative Care (CPPPC) was developed to support primary care professionals delivering PC. It is important to know how FP experience giving usual care to PC patients, in order to understand the possible effect of the CPPPC.

**Aims:** To understand which facilitators and barriers are perceived by FP to deliver high quality PC.

**Methods:** The CPPPC is implemented in 5 Belgian areas (2 Dutch-speaking area, 2 French-speaking areas and the bilingual Brussels area). Per area and before implementation, a focus group with FD will discuss facilitators and barriers for FD to deliver high quality PC.

**Results:** Focus groups have been done in 2 areas; more are planned in November 2014, March and September 2015. Main results of focus groups in 4 areas will be presented during the conference. Many FPs define high quality PC as communicating the PC status 'timely' to patients and team members, having a good knowledge of symptom control and collaborating well both with patients and informal care givers, and with primary and secondary care professionals. PC patients deserve a higher level of continuity of care compared to others.

Facilitators for this ideal of delivering PC are:

- working with a good team, whether in the nursing home or in home care
- working in a group practice
- a 'health care culture' accepting the concept of advance care planning
- instruments helping FP to discuss the patient's prognosis and PC needs with the patient and with colleagues
- financial support measures for PC patients at home

Barriers to provide high quality PC are:

- the taboo of 'palliative care' is diminishing slowly, but is still present also in family doctors
- the understanding of PC as 'care for the dying'
- fragmented care in home care compared to care in the nursing home

**Conclusions:** The main issue to improve the quality of PC seems to be its taboo nature.

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**Abstract type:** Poster

## Case Conferences between General Practitioners and Specialist Palliative Care Teams in End Stage Heart Failure or Lung Failure Reduces Service Utilisation

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**Background:** Non-malignant diseases cause many more deaths than cancer, but most palliative care service patients have cancer. Determining how to manage the end of life phase of non-malignant disease is still uncertain. Australian General Practitioners (GPs) can be remunerated for participation in multidisciplinary case management conferences.

**Aims:** To determine the effectiveness of formal case conferences between General practitioners and specialist teams to develop case management plans for end stage heart and lung disease patients.

**Methods:** Patients are identified by hospital heart failure and lung health nurses. A single case conference between the nurse, the patient's GP and a Palliative Medicine specialist was conducted using a structured format to produce a care plan with clear responsibilities negotiated. Patient and carer needs are discussed. Chart audit of hospital records and GP records to determine service utilisation rates before and after the case conference, and adherence to the recommendations raised in the case conference.

**Results:** Twenty-four patients eligible, 23 case conferences with 21 GPs conducted between November 2011 and November 2012. One GP refused to participate. Ten patients died, three at home. Of 82 management recommendations made, 55 (67%) were enacted. ED admissions fell from 13.9 per annum (pa) to 2.1 (difference 11.8, 95% CI 2.2–21.3,  $p = 0.001$ ); ED admissions leading to discharge home from 3.9 to 0.4 pa (difference 3.5, 95% CI -0.4–7.5,  $p = 0.05$ ); hospital admissions from 11.4 to 3.5 pa (difference 7.9, 95% CI 2.2–13.7,  $p = 0.002$ ); and length of stay from 7.0 to 3.7 days (difference 3.4, 95% CI 0.9–5.8,  $p = 0.007$ ).

Participating health professionals were enthusiastic about the process.

**Conclusion:** Case conferences appear to improve service utilisation markedly. This appears to be due to comprehensive case review, better interdisciplinary communication and clear role delineation. A formal RCT will be conducted to confirm the finding.

**Abstract number:** P2-350  
**Abstract type:** Poster

## Qualitative Study of Australian GPs and Palliative Care Practitioners on the Role of General Practice in End-of-Life Planning and Care

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**Background:** End-of-life care provided by general practitioners (GP) has been shown to be effective, especially with support from specialists and nurses. This involves the identification of patients at risk of dying and the planning and provision of end-of-life care. However, the acceptability and feasibility of implementing such a program in Australia have not been well studied.

**Aims:** To explore the views of GPs and palliative care practitioners on the role of general practice in identifying patients at risk of dying and planning and providing end-of-life care.

**Methods:** Semi-structured telephone interviews with purposive sampling of GPs, and palliative care physicians and nurses. The GPs were drawn from a study examining the accuracy of the GPs in identifying patients who are at risk of death. Interviews were recorded

using a voice recorder and transcribed. The transcripts were analysed using a qualitative description method. Selected transcripts were independently coded and discussed with other members of the research team to increase the reflexivity of the primary analyst. UNSW and University of Queensland Human Research Ethics Committees approved the study.

**Results:** Twenty-one participants (11 GPs, 5 palliative care physicians, 5 nurses) were interviewed. Participants reported that general practices play a key role in the planning and provision of end-of-life care. Palliative care practitioners had a largely supportive role, becoming actively involved when the patient has complex or uncontrolled symptoms, or are suboptimally managed by the GP. A number of barriers and enablers to effective planning and care were identified.

**Conclusion:** The participants felt that general practices should play a key role in the identification of patient at risk of death, and the planning and provision of end-of-life care. However a number of barriers need to be addressed.

**Funding:** Primary Care Collaborative Cancer Clinical Trials Group (PC4) / RACGP Foundation.

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## A National Wide Survey of Medical Rehabilitation Professionals Staffing in Palliative Care Teams of Core Cancer Treatment Hospitals in Japan

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**Background:** In Japan, based on cancer control act 2006, palliative care is provided with cancer treatment concurrently.

The core cancer treatment hospitals (CCTHs) which started in 2006 should take a leading part of cancer treatment all over Japan, totally 397 hospitals at 2013, one of the criteria has set up with palliative care team (PCT). That shows needs of Palliative care for cancer patients.

**Aims:** To investigate staffing about medical rehabilitation professionals (MRPs), in PCT of Japanese CCTHs in 2013.

**Methods:** We accessed 397 CCTH's homepages to collect data about staffing of MRPs in PCT at the end of December 2013. Then, we analysed the data statistically.

**Results:** We found out they have 396/397(99.7%) of MRPs and 394/397(99.2%) of PCT in CCTHs.

The CCTHs take not only patients with cancer but also others, such as CVA, Fracture, SCI, and so on.

145/397(36.5%) of CCTHs have posted MRPs as a member of PCT. Focusing on Japanese associations of cancer centers (JACCs), 9/32(28.1%). JACC started in 1965, their experience is older than CCTH.

**Discussion:** In this survey, the ratio of MRPs in PCT are 28.1% of JACC, and 36.5% of CCTH. In other survey reported by Abe at 13<sup>th</sup> world congress of EAPC, the ratio was 58.8% of hospital (231/393).

So, the more hospitals specialise in cancer treatments by top-down theory, the less MRPs in PCT. In other words, the more hospitals based on the needs of the patient and community by bottom-up theory, the more MRPs in PCT.

PCT registration of JSPM has increased to 491 hospitals in May 2014, and the ratio of MRP in PCT is still 60%, the tendency has been similar.

**Conclusion:** We conclude MRP staffing in PCT does not meet the needs of cancer patients in Japan.

**Abstract number:** P2-352  
**Abstract type:** Poster

## Dying out-of-hours in the UK: A Integrative Review on Experiences of Patients, Carers and Professionals

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**Background:** To eliminate the time variation in quality of care, the call for 24/7 end-of-life care service provision promoted development of various service models to support dying patients at home in the UK. Yet, no systematically derived evidence is available to narrate the role of out-of-hours palliative and end-of-life care services.

**Aim:** This review aimed to synthesise the current published evidence regarding the experiences of dying patients, relatives and healthcare professionals in provision and quality of palliative and end-of-life care during out-of-hours.

**Design:** Using standard process of data evaluation and extraction, an integrative review conducted to synthesise relevant evidence.

**Methods:** Using consensual agreed search terms, five data bases (PubMed, CINAHL, PsycINFO, AMED and SocIndex) and hand search of selected journals and of reference lists were searched during May 2014. UK-based both qualitative and quantitative studies were screened for their eligibility and methodological quality before they were included in final analysis.

**Results:** In total of 18 studies (10 quantitative, 6 qualitative and 2 mixed methods) were included in our review. Thematic analysis revealed five themes: less-trained workforce, proactive versus reactive service designs, hesitant patients and carers, unfamiliar care environments and geographical challenges.

**Conclusion:** This review has identified that there is minimal evidence available on effectiveness in quality, composition and nature of out of hour's services. Geographical inequalities in the service designs often challenge patients to achieve their preferences at their last days of life. With a limitation to existing quality of evidences, further robust comparative evaluation urgently needed to gain national consensus in providing quality of end-of-life care during out-of-hours in the UK.

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**Abstract type:** Poster

## Treat...Treat: The Philosophical Divergences of End of Life Care in Critical Care Units

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**Background:** Around 52% deaths in the UK occur within a hospital setting, with a significant proportion of these being in critical care settings. Specifically, 15% to 36% of patients admitted into an intensive care will die. Despite the implementation of clinical guidelines such as the Liverpool care pathway (LCP), facilitating end of life care in critical care settings remains a challenge for critical care practitioners.

**Aim:** This study aimed to explore experiences, challenges and practices of critical care practitioners in delivering end of life care in critical care settings since the discontinuation of LCP.

**Methodology:** A qualitative exploratory design was used. After full ethics approval, semi-structured interviews were conducted with fourteen critical care practitioners from two acute NHS trust hospitals in England.

**Findings:** Framework based data analysis revealed five key themes of philosophical divergences in end of life care in the critical care setting. These themes included distinctive patients, defying setting, divergent dying trajectories, feeling useless and new directions. The themes explored how the nature of critical illnesses, trajectory of death, patient characteristics, and new directions challenged the delivery of end of life care in critical care settings. Participant's described unique challenges of defying the philosophy of 'critical care' and changing contexts from treatment to palliation infusing a feeling of uselessness in delivering quality end of life care.

**Conclusion:** This study found that the curative philosophy of critical care and the rapid end of life trajectory often negates the 'negotiation of a natural death' in critical settings. Educational interventions both in pre and post registration health care practice need to be developed to tackle these philosophical divergences of care delivery in critical care settings.

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**Abstract type:** Poster

## Communication, Interaction and Coping of Cleaning Staff with Seriously Ill and Dying Patients

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**Background:** Although the palliative care team traditionally consists of professionals specialised in this field (e.g., physicians, nurses, psychologists, social workers), other professional groups within the hospital (e.g., receptionists, secretaries, cleaning staff) often have frequent contact with patients and may help to improve the overall care of patients.

**Aim:** We were interested in how cleaning staff (CS) communicate and interact with seriously ill and dying patients. In addition, we investigated how CS cope with the situation of death and dying and whether there is a need for additional support to deal with this aspect of their work.

**Methods:** A sequential mixed methods design was chosen. At a large university clinic in Germany, CS and cleaning management staff were recruited for interviews and focus group discussions. Questionnaires were given to all CS (n=240) working at the clinic in September 2008. Interviews and focus group discussions were content analysed and results were used to create a questionnaire. Quantitative data was submitted to descriptive analysis.

**Results:** In interviews and focus group discussions, CS described interactions with patients as an important and fulfilling aspect of their work. In total, 124 questionnaires were returned. About half of participants indicated that patients talk with them every day, on average for 1–3 minutes. Although the most common topics of conversation included weather and family, patients also discussed their illness and, occasionally, thoughts regarding death. When patients addressed illness and death, CS often felt uncomfortable and helpless.

**Conclusions:** Cleaning staff perceive that they have an important role in the clinic – not only to clean but also to support patients. Likewise, patients seem to appreciate being able to speak openly with CS. Still, it appears that CS may benefit from additional training in how to communicate with patients about sensitive issues such as illness and death.

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**Abstract type:** Poster

## Describing the Content of 'Early' Specialised Palliative Care (SPC) in the Danish Palliative Care Trial (DanPaCT) – Which Interventions were Initiated and for Which Symptoms and Problems?

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**Background:** It is now often recommended that patients should be referred to SPC at an earlier time in their disease trajectory than what has traditionally been the case. However, little is known about what early SPC consists of.

**Aims:** The aim of this study was to describe the content of early SPC in DanPaCT.

**Methods:** DanPaCT investigates whether patients with metastatic cancer, who reported palliative needs in a screening, would benefit from being referred to early SPC. Patients were either randomised to standard oncologic treatment or standard oncologic treatment plus SPC (the intervention group). For patients in the intervention group the medical records for the eight weeks of the trial were coded based on a coding scheme to describe the interventions given. In the coding scheme each coding consisted of an action (e.g. an intervention) attached to a symptom or problem and to a profession.

**Results:** The results from 44 of the 145 patients, who were randomised to the intervention group show that 37 (84%) of these patients received at least one intervention. In total 183 interventions were given to the 37 patients (mean = 5 per patient; range 1 to 22). Of the 183 interventions 58% were medical prescriptions, 20% were therapeutic conversations, and 7% were referrals to other specialists. Of the 37 patients who received at least one intervention, 54% of the patients were given an intervention at least once for pain, 38% for financial difficulties, 30% for emotional function and 22% for constipation.

**Discussion/conclusion:** Early SPC consist of medical treatments in more than half of the interventions given, and the symptom that was most often treated was pain. We discuss the challenges of coding the psychosocial content of the interventions. Some patients (16%) never received any intervention from SPC.

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## Using Emotional Touchpoints to Explore Attendees' Experiences of Specialist Palliative Day Services

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**Background:** Qualitative evidence suggests that attending a specialist palliative care day service (SPDS) has a positive impact on the wellbeing of attendees. However traditional qualitative interviews vary in intensity and as such they may not capture a full range of emotions that care experiences engender. Emotional Touchpoints (ET) is a novel approach to exploring patients' stories of their care experiences where both the positive and negative aspects of such care are explored in a face to face interview using a more structured approach.

**Aim:** To Explore the Impact of Attending SPDS on Attendees' Wellbeing.

**Methods:** This is the qualitative phase of a larger mixed-methods study. Using a phenomenological framework 15 SPDS attendees from two different SPDS took part in a single audio-recorded ET interview. The data was then subjected to interpretative thematic analysis to explore the impact of attending SPDS on wellbeing. Member checking, in the form of providing each participant with a copy of their story, took place to ensure accuracy of the researcher's understanding of what was said.

**Results:** The final interpretation of the data will be ready to report in January 2015. From early analysis it would appear that attending SPDS makes attendees feel safe and allows them to talk openly to fellow attendees and staff about issues that people who are not ill and are 'in the outside world' do not want to hear about. It would also seem that seeing other people who are 'in the same boat' coping with illness or being helped by expert staff helps attendees face their own future which in turn reduces anxieties.

**Conclusions:** These will be drawn from the final data analysis which is ongoing.

## Policy

**Abstract number:** P2-357

**Abstract type:** Poster

### Challenges in Preparing Advance Directives and Advance Care Planning for Dementia Patients: Summary of Issues for Policy Discussion in Japan

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**Background:** Decision making for dementia patients is a global problem. In some countries, including England, preparing advance directives (ADs) and/or advance care planning (ACP) before one loses the capacity to do so is considered important. Indeed, some countries already have AD-related laws. However, 'Orange Plan', a national dementia strategy in Japan, makes no mention of either ADs or ACP, and neither is legally binding.

**Aim:** This study aimed to

- 1) clarify dementia-specific challenges in preparing ADs and ACP, and
- 2) consider specific measures and policies implemented in England to clarify issues for policy discussions in Japan.

**Method:** Comprehensive literature review. PubMed and EBSCOhost databases were searched and relevant public reports and academic guidelines were added.

**Results:** Four major challenges were identified:

1. Dementia-specific medical issues (delays in diagnosis; perception that dementia is a life-limiting disease and the opposite perception);
2. Capacity for decision-making;
3. Difficulty maintaining or improving Quality of Life (acknowledging dementia to be a loss of personhood; inadequate provision of palliative care); and
4. Dependency on others, including family and proxy decision makers.

Measures to address these challenges in England include indicating core policy direction under the Prime Minister's initiative, setting policy targets and NICE quality standards, increasing research funding, and leading research and education via charities such as Alzheimer's Society and the National Council for Palliative Care.

**Conclusion:** Based on lessons from England, the Ministry of Health, Labour and Welfare of Japan initiated a model project for early intervention. Japanese policy makers should consider establishing a new department controlled by the Prime Minister to address the aforementioned issues, ensure an annual budget for cross-cutting activities, make early ACP and/or AD preparation a policy target, and discuss the drafting of AD-related laws.

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**Abstract type:** Poster

### A New Framework for Palliative Care in Switzerland: Getting a Common Basis for the Implementation of Palliative Care within the National Strategy for Palliative Care

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There is an ongoing discussion worldwide on what palliative care really is. This complicates the implementation of palliative care into health services: how can a new system be set up, financed and publicised if it cannot actually be described? As part of the Swiss National Strategy for Palliative Care, a Framework for Palliative Care has been developed. It is intended to build a common thread running through all areas covered by the National Strategy, from health services issues to education, finances, awareness and research.

In a first step we reviewed literature with specific focus on attempts to give a clear definition of palliative care. Second, a working group was set up, composed of fourteen members with background in different disciplines. The document was drawn up in three full-day sessions including chaired group discussions. An online questionnaire has been set up and will determine the extent to which the framework is used and how it is perceived.

The framework describes the implementation of palliative care in four different domains:

- the specific **target groups** of palliative care and their requirements
- the **service offers and interventions** necessary to meet the needs of each target group
- the **care structures** required to provide these services
- the **competencies** required to accomplish these tasks in high quality

We defined three levels of expertise in each domain which partly differ from the EAPC white paper: palliative care awareness, general palliative care and specialist palliative care. A major point is the systematic integration of the population as a specific target group.

The Framework for Palliative Care in Switzerland provides a mapping system to locate the wide range of different tasks in palliative care. It provides guidance and can serve as a working tool for all persons and institutions involved in the implementation of the National Strategy for Palliative Care. Results of the online questionnaire will help to specify its impact.

**Abstract number:** P2-359

**Abstract type:** Poster

### The Place of 'Place' of Death in the Netherlands

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**Background:** Most (73%) of the Dutch population prefers to die at home; yet only 32% were able to so in 2006. Since then, the number of palliative terminal beds and the provision of

public information about the possibilities of palliative care have greatly increased.

**Aims:** This study explored shifts in the selection of places of death from 2004 to 2013 and the meanings assigned to individual agency and illness that play a role in these shifts. The purpose of this study is to contribute to the dialogue between professionals, scientists and policymakers about the concept of autonomy and personal choice about the place of death.

**Mixed methods:**

**Quantitative:**

National survey (n = 1881)

Palliative care patients in hospices (n = 41)

Central Bureau of Statistics: mortality statistics of people with chronic illness (not sudden death)

**Qualitative:**

Retrospective study: semi-structured interviews with survivors (n = 20)

**Analysis:**

Quantitative: Chi-square test; the Spearman Rank Correlation Coefficient

Qualitative: Open and axial coding, using a reiterative process.

**Results:** The gap between desire to die at home and reality has decreased in the last 10 years. The current gap seems to be partly due to different definitions of 'home'. Those in the last phase of life attached more importance to 'feeling at home' than 'being at home'. Feeling in control about dying was more a relational process of sense making than an individual act. Dialogue and sense making about the meaning of dying preceded and were considered more important than decision-making.

**Conclusions:**

The process leading to the realisation of the place of death is not linear but complex.

Decisions can change over time.

Professionals should attach more importance in realising the wishes of patients than to influencing their decision-making.

Relational care requires dialogue of sense making between all participants in the dying process.

*The survey was financially supported by VPTZ Nederland*

**Abstract number:** P2-360

**Abstract type:** Poster

### Access to Opioid Medicines: A Methodological Framework for Analysing Policy Barriers

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**Background:** The World Health Organization (WHO) defines the 'principle of balance' in controlled substances policies to ensure that opioid medicines are available for patient care while preventing their abuse. However, national policies often strongly emphasise control and restriction, thereby interfering with medical availability of opioids.

**Aims:** To develop a methodological framework for the systematic analysis of policy barriers to accessing opioid medicines in twelve European countries.

**Methods:** Data for qualitative action research were collected throughout the Access To Opioid Medication in Europe (ATOME) project in collaboration with national country teams. Documents developed during the project, such as protocols of national problem analyses, strategic action planning worksheets, and minutes of national ATOME conferences were analysed using qualitative content analysis. A category system was developed based on the literature, public health models, and WHO policy guidelines, and validated by experts from pharmaceutical policy. The identified policy barriers were sent to the national teams for verification.

**Results:** Four major categories of barriers were defined:

- (1) policy and regulation;
- (2) financial and economic aspects;
- (3) knowledge and education; and
- (4) social awareness.

Within each category, a hierarchy of sub-categories was identified evidencing specific barriers to accessing opioid medicines for pain relief, palliative care, and treatment of opioid dependence.

**Conclusion:** The methodology provided a useful framework for the analysis of policy barriers. Regular communication with country teams helped to create ownership of the resulting recommendations. Limitations were that 'thickness' of data depended on the commitment of national key contacts, and consensus on the impact of barriers was not always reached. To ensure that the identified barriers validly represent a country's situation, dialogue with a broader range of stakeholders would be necessary.



Abstract number: P2-361

Abstract type: Poster

### Who Are Demanding Changes in the Russian Public Agenda?

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**Background:** For many years, the problem of inadequate pain relief was denied by the Russian Ministry of Health, despite the low level of opioid consumption for medical and research purposes: 2.04 ME mg/capita. The problem moved into the public agenda this year when the State Duma (Congress) passed on the first hearing proposed changes to the existing law on narcotic drugs, the government held a meeting concerning the availability of opioids, and the Ministry of Health displayed an interest in the problems of accessibility of opioids in various regions of the country.

**Aim:** Identification of Russian agenda builders who demanded change.

**Methods:** The analysis of information in social and professional media: newspapers, press releases, TV, radio, and identification of the sources that promoted change.

**Results:** Media exposure of the suicide of Admiral Apanasenko and the criminal conviction of Doctor Khorinyak were catalysts in altering the public's attention to access of opioids and made people sensitive to the issue. Russian Association for Palliative Medicine representatives did not comment on the issue. Physicians, who are governmental employees in Russia, failed to be open about their opinions. As a consequence, only a small group of palliative care advocates had the opportunity to provide indisputable facts to the media that helped the Russian public and policy makers understand the size of the problem. Assistance from Human Rights Watch and the European Association for Palliative Care gave confidence to these advocates of their rightness.

**Conclusion:** In the current political environment, the role of the professional medical community was minimal. Assistance from international organisations was a necessity. Mass media exposure critically modified the dynamics of the policy-making process. At a time when the democratic institutions in Russia do not work properly, a World Health Organization investigation on the availability of opioids for pain relief is vital.

Abstract number: P2-362

Abstract type: Poster

### Building Bridges with the General Public: Palliative Care and Media

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**Aim:** The aim of this presentation is to highlight the importance of working with media, to overview possible ways of engaging with the general public and to provide an example of a successful online public campaign, including challenges with its realisation.

**Design, methods and approach taken:** Thinkaboutdeath.org is an online campaign offering an opportunity to contemplate one's last wishes and to create a list of last wishes, which can be shared via social media with friends and family. It was developed by a hospice Cesta domu, based in Prague, the Czech Republic, and a creative agency Yinachi. After the success of the initial Czech version (Mojesmrt.cz), the EAPC granted their auspices for developing an international version in English.

**Results:** In the first four weeks of the campaign, more than 20 000 users visited the website, 7500 of them engaged in the core part focused on creating a list of your last wishes. Average session duration is 13 minutes, which can be considered as a major success with regard to the usual web traffic. 40% of visitors are between 25–45 years of age, 29% are older than 45. All types of media, both local and international, have published stories about the campaign, broadcasted various TV spots and organised a number of interviews and discussions with experts, journalists and policy makers on the topic of end of life care.

**Conclusion / lesson learned:** Working with media is crucial in developing a relationship between professional community and the general public, consisting also of future patients and clients as well as policy makers. Thinkaboutdeath.org is an example of a successful online campaign aimed at rising the awareness of issues related to death and dying in the general public, developed with a limited budget and having a potential of high impact on the society and policy makers. The campaign will be followed by an advanced module, which will serve to create a legally binding advance care planning document.

## Public health and epidemiology

Abstract number: P2-363

Abstract type: Poster

### Is Cancer Patients' Admittance to Specialised Palliative Care Related to Sex, Age and Cancer Diagnosis? A Study from the Danish Palliative Care Database (DPD)

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**Background:** Denmark has no national guidelines for referral of patients to specialised palliative care (SPC) and little is known about the referral patterns. A previous Danish study of advanced cancer patients found no major differences in symptoms and problems in relation to sex, age and diagnosis. Therefore, one could hypothesise equal admittance to SPC in relation to sex, age and diagnosis.

**Aim:** To investigate whether admittance to SPC in Denmark varies for adults dying of cancer in relation to sex, age and diagnosis.

**Methods:** The study is a register based study on Danish adult patients who died from cancer in 2010–12 (N=44,548). Data sources: The Danish Register of Causes of Death, the Danish Cancer Registry and the Danish Palliative Care Database. The associations between the explanatory variables (sex, age and diagnosis) and admittance to SPC were investigated using logistic regression.

**Results:** More than one third (37 %) of the patients who died of cancer in 2010–12 in Denmark were admitted to SPC. Women were more likely admitted to SPC than men (OR=1.23; 1.17–1.28). The odds of admittance decreased with increasing age, the odds of admittance to SPC were over six times higher for the youngest (18–40 years old) compared to the 80+ years old (OR=6.44; 5.19–7.99). In relation to diagnosis, the highest odds ratios were found for individuals with sarcoma 1.90 (1.52–2.38), pancreatic 1.77 (1.61–1.94) and stomach cancer 1.69 (1.50–1.90) and lowest for the hematological malignancies (OR compared to 0.33 and 0.50) compared to the average of all diagnoses.

**Conclusion / Discussion:** In this first national register based study of admittance to SPC, we found that admittance to SPC varied in relation to sex (lowest for men), age (lowest for the 80+ years old) and cancer diagnosis (lowest for haematological malignancies).

Abstract number: P2-364

Abstract type: Poster

### Place of Death is Influenced Not Only by Cause of Death, but Also by Age and Gender – A National Cohort Study

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**Background:** In the health care system's organisation of palliative care, it is of interest to know which factors influence place of death. In Denmark, a nationwide registry for causes of death allows for epidemiological analyses in the whole nation.

**Aims:** To investigate whether causes of death were evenly distributed among persons dying in hospitals or at home, and to analyse which factors play a role in place of death in the Danish adult population.

**Methods:** A cohort study using the national registry for causes of death during the period 2007 – 2011. All natural causes of death in hospitals and at home, among persons aged 19+, were included (N=195,158), except rare causes (N=5,358). The outcome for the analyses was death in hospital compared with death at home.

**Results:** The major cause for death was cancer (32% among all). For persons younger than 86 years, 69% died in hospitals, and 37% died from cancer. For 86+, 57% died at home, 27% died from heart disease, and 13% from cancer. Infections and respiratory diseases had significantly higher odds-ratios for hospital death, compared with cancer; 3.35[3.06;3.67] and 1.29[1.25;1.33] respectively, while heart diseases and psychiatric causes were significantly lower; 0.81[0.78;0.83] and 0.13[0.12;0.14]. Male gender was an independent factor for hospital death (odds-ratio 1.13[1.11;1.15]). Age influenced death in hospitals, regardless of cause or gender, with odds-ratios of 1.32[1.29;1.35], 1.38[1.26;1.51] and 0.50[0.49;0.51] for age groups; 40–64, 19–39, and 86+ (ref-age: 65–86).

**Conclusion / Discussion:** The causes of death had a major impact on place of death. However, both age and gender independently influenced place of deaths. It may seem obvious that the cause of death plays a role for place of death, and these results can help the dimensioning of palliative care initiatives. However, it is suggestive that both age and gender are independent factors for place of death – which seem to call for more qualitative explanations.



**Abstract number:** P2-365  
**Abstract withdrawn**

**Abstract number:** P2-366  
**Abstract type:** Poster

## Ten-year Trends in the Risk of Hospital Death for Conditions Needing Palliative Care: A Death Certificate Study

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**Background:** Most people die in hospital despite a preference to die at home. Understanding trends and factors is key but most evidence is from regions where palliative care is well-established.

**Aims:** To examine the risk of hospital death for conditions needing palliative care over a 10-year period in a country without integrated palliative care.

**Methods:** Death certificate study of all 1 041 596 deaths from residents aged ≥18 years (2003–12, Portugal). Criteria for palliative care need were cause of death (ICD 10 codes) cancer, heart and cerebrovascular, renal, liver, respiratory or neurodegenerative diseases, dementia/Alzheimer's/senility, or HIV/AIDS. For this group, we studied trends and factors associated with dying in hospital using multivariate logistic regression.

**Results:** 736 454 (70.7%) of deaths met the criteria for needing palliative care [51.2% men, median age 80; heart and cerebrovascular diseases (43.8%), cancer (32.2%)]. 61.8% of these deaths occurred in hospital, 36.8% of which outside the patient's municipality of residence. The odds of dying in hospital increased by year (AOR 1.04, 95%CI 1.04–1.04), with age- and gender-standardised percentages rising from 56.3% in 2003 to 66.7% in 2012. Odds were higher for the married and those dying from HIV/AIDS (3.18, 2.91–3.48), renal (1.57, 1.51–1.63), liver (1.49, 1.44–1.55) or respiratory diseases (1.45, 1.43–1.48) versus cancer. Odds were lower for heart and cerebrovascular (0.48, 0.48–0.49) and neurodegenerative (0.41, 0.40–0.44) diseases, dementia/Alzheimer's/senility (0.13, 0.13–0.13), and for older people.

**Conclusion:** We found an upward trend of hospital death and higher risk for the married, findings that are opposite to countries where palliative care is well-established. In addition, there is wide variation in the risk of hospital death among patients with non-malignant conditions. This clinical heterogeneity requires attention from care, policy and research.

**Funding:** Calouste Gulbenkian Foundation.

**Abstract number:** P2-367  
**Abstract type:** Poster

## Where Do People Die in Sweden? A Population-based Study of the Distribution and Determinants of Place of Death

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**Background:** Place of death, with home reported to be the most desirable place, is considered to be one important aspect of quality of care at the end of life. Sweden, until now, lacks population-based studies that not only examine place of death, but also what factors that may influence where people die.

**Objectives:** The objectives were to examine place of death in Sweden and associations between place of death and diagnosis, personal characteristics, geographical and socioeconomic factors.

**Design and methods:** This study, being part of the International Place of Death (IPoD) project, was based on all deaths in Sweden 2012 ( $n = 91874$ ). Data was derived from death certificates and population-based registers. Distribution of place of death and other variables were analysed descriptively. Binary logistic regressions were performed to examine factors associated with dying in hospital, at home and in nursing homes.

**Results:** Of all deaths in 2012, 42.1 % died in hospital, 17.8 % at home and 38.1 % in nursing homes. Being married and having higher education increased the likelihood of dying at home, whereas living in an urban area decreased the likelihood of dying at home. Being old, and dying from Dementia increased the likelihood of dying in nursing home. In fact, the majority of individuals >90 years (61.9 %), and with dementia (89.8 %) died in nursing home, while most (74.5 %) children 0–17 years died in hospital.

**Discussion and conclusions:** In Sweden, people likely to be in need of palliative care continue to die in hospitals, and many old individuals die in nursing homes. While dying in hospital has been associated with risk of futile treatment, previous studies also report lack of palliative approaches in nursing homes. The geographical and socioeconomic differences in place of death call for further attention. As the Swedish national guidelines for palliative care were launched in 2012, these results provide important baseline information to evaluate its effects.

**Abstract number:** P2-368  
**Abstract type:** Poster

## Common Attributes of Patients with Advanced Chronic Disease who Would Benefit from Palliative / Hospice Care

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**Aim:** To establish the characteristics of patients who could benefit from early access to palliative / hospice services, we identified the attributes of patients commonly hospitalised / re-hospitalised with renal failure, sepsis, congestive heart failure, chronic obstructive

pulmonary disease and pneumonia.

**Methods:** We conducted a retrospective analysis of the US Center for Medicare and Medicaid Service (CMS) data for patients living in central and southeast Ohio (approximately 500,000 Medicare beneficiaries). We identified index hospitalisations for each of these five conditions, described co-morbid conditions using Agency for Healthcare Research & Quality clinical classifications software, and evaluated the characteristics of patients with a risk of dying within six months. The resultant models for each of the five conditions had significant and different covariates.

**Results:** The adjusted odds ratios of eight attributes were common to these five conditions, and associated with a risk of dying within six months, including:

Congestive heart failure without hypertension, odds ratio 1.347–1.507  
Respiratory failure with insufficiency or arrest (adult), odds ratio 1.295–1.689  
Chronic renal failure, odds ratio 1.172–1.441  
Chronic ulcer of skin, odds ratio 1.46–2.268  
Secondary malignancies, odds ratio 5.115–7.068  
Nutritional deficiencies, odds ratio 1.915–2.205  
Delirium, odds ratio 1.329–1.893  
Discharge to a Skilled Nursing Facility, odds ratio 1.483–2.152

**Conclusions:** These eight attributes that are associated with an increased risk of six-month mortality after discharge from a hospital, and common across these five chronic conditions, can be used to identify patients who could benefit from early referral to palliative and hospice care services earlier, and measure the timely utilisation of these services within a population of patients at risk of dying within six months.

## Spirituality

**Abstract number:** P2-369  
**Abstract type:** Poster

## Pastoral Care of the Dying: What Pastoral and Religious Support Is Offered to Dying People by Clergy? A Pilot Study among Ordained Clergy in Lambeth and Southwark, South East London

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**Background:** Religious and spiritual needs of patients and families are an important aspect of care for people at the end of life. Many people who are dying wish to die at home. The research sought to explore the attitudes of community clergy towards caring for dying people. The study described participant's education, theological understanding of dying, knowledge of and involvement with hospices, and experience of caring for dying people. Participants were invited to complete a Death Anxiety Scale to assess personal attitudes towards dying.

**Participants:** 14 clergy from 6 denominations (Church of England, Roman Catholic, United Reformed Church, Methodist, Baptist and the Salvation Army) were recruited.

**Data collection and analysis:** Each participant was interviewed and the interview was recorded, transcribed and entered into NVivo for data analysis. The Death Anxiety Scale results were also entered into NVivo. Themes arising from the interviews were coded.

**Findings:** Participant's described little contact with hospices and hospices. The Roman Catholic participants were active in visiting dying people as the Sacramental care of those at the end of life was considered a task for the priest. When invited to describe what religious care includes participants described a terminology of pastoral care. Invited to do the same for spiritual care, practical help was involved. No participant understood spiritual care in a way used in end of life care settings. Participants described their personal and professional experiences of caring for dying people. Personal bereavement meant less engagement with dying people and a high DAS score. Participant's described a lack of support to discuss their work with dying people.

**Recommendations:** The implications for practice are

- Training events to improve confidence and skill.
- Relationships between hospices and training institutions.
- 'Support' meetings for clergy.
- Relationships between clergy and hospices.

**Abstract number:** P2-370  
**Abstract type:** Poster

## Innovation in Cancer Management Spiritual Care and Changes in Receptor Gene Expression in Breast Cancer Patients

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Breast cancer is the most common cancer in females in Iran and in most of the developed countries. Behavioral and clinical studies have shown that having chronic stress and impaired mental and spiritual condition of each individual predispose several types of cancer including breast cancer. Research results showed that religious and spiritual factors correlate with indices of physical consequences such as heart disease, cancer and death. Also, there is a confirmed relation between psychiatric conditions and changes in receptor gene expression in depression anxiety and social dysfunction. Different studies demonstrated the role of neurotransmitters in occurrence and progression of cancers. They affected cells by their various types of receptors. In accordance with our previous studies, the most effective genes in psychiatric conditions and thus physical conditions are Dopamine and Serotonin receptors. Accordingly, the study was conducted to evaluate effects of spiritual therapy on changes in Dopamine and Serotonin receptor gene expressions in breast cancer patients and hence, determine specific gene receptors to be held responsible.

90 female volunteers, were selected to run the study. It was observed that DRD2-DRD4 in intervention group PBMC decreased compared to the control group and even lower than those of healthy individuals. Moreover, real-time PCR data indicated significant promotion in expression of 5HT3AR and 5HT2AR in PBMC in breast cancer. Our results indicated significant reduction in expression of 5HT3AR and 5HT2AR in intervention group compared with the control group but there were no significant changes in comparison with healthy samples. The findings were of great significance in prevention and treatment of cancer because they revealed the possibility of using other types of treatments such as spiritual interventions apart from conventional medical treatments.

**Abstract number:** P2-371  
**Abstract type:** Poster

## Sustaining Hope and Life Courage – The Impact of Care

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**Background and aim:** In the Western World ovarian cancer is the leading cause of death from a gynaecological malignancy. Consequently, women with ovarian cancer can have palliative needs right from the beginning of their treatment. In this study we explored embodied experiences of comfort and discomfort as they develop during the final diagnosis of ovarian cancer and the commencement of treatment.  
**Methods:** The study took place in a Danish regional centre for surgical treatment of gynaecological cancer. A number of nineteen qualitative research interviews were conducted. By applying a phenomenological-hermeneutic text interpretation methodology, the findings were systematically identified, put into meaning-structures, interpreted, and critically discussed.  
**Results:** The women were hoping for survival, but also, if this was not possible, for dying with dignity and a minimum of suffering. To possess life courage seemed crucial in order to go on living, even though life was tough, and at the same time prepare for dying even though life was wonderful. The empirical material constituted this main theme: 'Hope and life courage are created in the interplay between body and mind'. These findings dealt with personal intentions, actions, reflections, and experiences in relation to the following subthemes: 'Experiencing discomfort', 'The impact of care' and 'Comfort and hope'.  
**Conclusions:** To be newly diagnosed and commence the treatment of a serious or late-stage cancer disease represents a period of time in life in which both hope and despair are present. Depending on the character of the disease intentions of patient involvement and shared decision making may be put under pressure during diagnoses and commencement of treatment, and whether a free treatment choice is an option can be questioned. Symptom relief represents a well-known and hope-enhancing strategy in palliative care. However, less emphasis has been put on this aspect in the beginning of the patient pathway.

**Abstract number:** P2-372  
**Abstract type:** Poster

## Palliative Care Training on the Spiritual Dimension: A Pilot in Teaching Hospitals in the Netherlands (SPIRIT-NL)

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**Background:** In the Netherlands palliative care (PC) is not a medical specialisation and non academic teaching hospitals do not have PC units. In these hospitals palliative care is delivered by healthcare professionals in curative departments, supported by PC consultation teams. A national multidisciplinary guideline (2010) on spiritual care (SC) focusses on SC delivered by all healthcare professionals in any setting where palliative patients are treated, supported by the specialists on this field: the healthcare chaplains.  
**Aims:** Implementation of the method of delivering multidisciplinary SC in PC as described in the guideline. Research questions: how to train doctors and nurses in assessing and responding to the spiritual and existential needs of their patients? Which spiritual assessment tools are consistent with the guideline, needs of patients and are operation able? What is the effect of training SC competencies to clinical teams? What is the effect on the perceived care and treatment as experienced by patients?  
**Methods:** Mixed method action research study, planned as an explorative multicentre trial: healthcare chaplains of 10 non academic teaching hospitals implementing a pilot training SC in PC to clinical teams. Qualitative and quantitative methods are used to analyse the effects of the intervention. The competences of the caregivers are measured pre and post (twice). Palliative patients on pilot and control departments are interviewed, pre and post intervention, using questionnaires on physical symptoms, spiritual distress and the perceived focus of caregivers on their spiritual needs, quest for meaning or existential questions.  
**Results:** The trial runs in two rounds, the results of the first group and part of the results of the second group of pilots will be presented at the conference.  
**Discussion:** Developing multidisciplinary SC in PC care requires joint commitment of healthcare chaplains, management, physicians and nursing staff.

**Abstract number:** P2-373  
**Abstract type:** Poster

## Improving Spiritual Support: Audit of the Assessment of Spiritual Needs and Delivery of Spiritual Care in those thought Likely to be Dying

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**Background and aims:** As good spiritual care begins with good spiritual assessment on two occasions the documentation of those considered sick enough to be dying was audited, particularly in relation to the assessment and provision of spiritual care. The aim was to improve the quality of both.  
The purpose of the baseline audit was to:  
• Assess a benchmark for spiritual assessment and delivery  
• Offer action points for improvement  
The audit cycle was completed to measure improvement following intervention.  
**Method:** The method employed for baseline and post intervention audits was to visit hospital wards and review a random selection of 20 individualised plans for the care of those thought likely to be dying.  
**Results:**  
• Spiritual assessment improved from 70% patients to 85% & 45% families to 50% from first audit to second  
• Identified spiritual needs improved from 40% patients to 55% & 35% families to 45%  
• 64% of those who requested pastoral support are documented as having received it compared to 50% previously  
• 30% of all patients received pastoral support whether or not the identified need was documented, compared to 20% previously  
• 60% of patients had a daily review of spiritual needs, compared to 50% previously.  
**Conclusion:**  
• Between audits visibility and accessibility of the Chaplaincy and Spiritual Care Service was increased by the distribution of posters and a chaplain doing a weekly ward round with the End of Life Facilitator.  
• Chaplaincy and spiritual care leaflets were inserted into all Individualised Plans for Care  
• Staff actively encouraged to make a spiritual assessment & acknowledged for doing so  
• Education offered to staff on spiritual assessment and the Trust's spiritual care policy  
• Input has been given on the re-writing of new documentation to support staff.

**Abstract number:** P2-374  
**Abstract type:** Poster

## 'Becoming Small together Around the Big Questions' – An Inquiry into how Philosophical Counselling and Socratic Dialogues and Communities of Wonder on Hospices Can Strengthen the Existential and Spiritual Care in Palliative Work

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In the contemporary research on existential and spiritual care in palliative work focus has mainly been on psychological and pastoral approaches, and to some extent also on aesthetic approaches. When 'spirituality' is described as what gives people balance when finding meaning in the existential challenges of life (Wright, 2005) it is surprising how little research there has been on the relevance of the practice of philosophy and *philosophising dialogues*, and especially the discipline of *philosophical counselling*, in palliative care. Based on a three-year phenomenological-oriented action research project on a Danish Hospice this paper describes how and why especially an *existential-phenomenological and action-oriented* research design was chosen and how this inquiry and cooperation (and co-creation) between the researcher and the nurses as 'wonder-driven co-inquirers' came out. The result of this action research project was partly on the methodological level a development of a kind of 'wonder lab', where the nurses through different forms of phenomenological writings and Socratic wonderments upon their written narratives of spiritual and existential moments in palliative care came up with some evocative and insightful insider-descriptions (or 'phenomenological snapshots') of these fragile and volatile but deeply meaningful life experiences and moments. On the other part some important research findings was also that the hospice nurses indeed were able to approach existential and spiritual questions and themes and situations in a more open sensitive and wondrous way than before, and that the ability to 'stand in the openness' in so-called Socratic Communities of Wonder also had an influence on the way they developed a new language and modes of being in dialogues around existential and spiritual issues or situations. This gave the nurses a new and more symmetrical and wondrous relation of 'being-with-the-other' in spiritual care.

**Abstract number:** P2-375

**Abstract type:** Poster

## Nurses Exploring the Spirituality of their Patients: An Observational Pilot Study in Palliative Care

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**Background:** Nurses have to give attention to all four dimensions of the patients they care for; physical, psychological, social and spiritual. Exploring the spirituality apparently isn't always easy. Nurses at the oncology department of a large university hospital in the Netherlands, are acquainted with the three questions of the Mount Vernon Cancer Network (MVCN) which might help them to explore the spiritual dimension of their palliative care patients.

**Aims:** This observational pilot study aimed at getting insight in if and how nurses recognise and take advantage of situations in daily care to talk about spirituality with their patients. Furthermore we want to find out whether the MVCN questions is part of this exploration.

**Methods:** The consultant spiritual care of the palliative care consultation team will tag along with several nurses in their daily work (3–6 shifts). Due to this participant observation technique, in which she wears a doctor's white coat, the caresituation remains as natural as possible. The consultant is well-known and esteemed at the department.

**Results:** The study is currently in progress and will be completed and analysed for the start of the conference. Therefore, no results are yet available. Results that will be presented focus on the following aspects:

- (1) caresituations in which nurses (might) interact with their patients about spirituality,
- (2) whether or not the MVCN questions play a role in that situations,
- (3) barriers and facilitators experienced by nurses regarding discussing spirituality with their patients.

**Conclusion / Discussion:** In order to support nurses in exploring the spiritual dimension of their patients, it is necessary to know what they do already in daily practice and what hinders or facilitates them. The results of our study will generate more insight in these processes and can thereby contribute to complete and integral nursing care for people in the last phase of their life.

**Abstract number:** P2-376

**Abstract type:** Poster

## How Do Palliative Care Doctors Ask Cancer Patients about Spirituality? A Qualitative Study

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Research indicates that patients would like their doctors to ask them about spirituality but it is not clear how such conversations are currently conducted.

As spiritual care is a recognised domain of palliative care, we aimed to discover how palliative care doctors currently ask their patients about spirituality, the impact of such discussions and what factors contribute to success.

This study used grounded theory methodology to explore the ways doctors discuss the topic of spirituality with their patients. Semi-structured interviews were conducted with 20 doctors in Australia and New Zealand who were involved in palliative care practice. They were asked to describe their usual practice and their views on facilitating factors and barriers as well as the impact of spiritual discussion on patient care. Snowballing was used to identify a wide range of perspectives. Interviews were transcribed verbatim, subjected to line-by-line coding and analysed for unifying themes.

Respondents described spiritual enquiry as a process over time which needs to be sensitive to individual patient needs. The doctor's own spirituality and self-care is critical to its successful practice. Spiritual discussion in palliative care can enrich relationships between the doctor, patient and their family, and is an important and effective intervention which can improve patient care by reducing symptom distress and supporting acceptance of approaching death. Facilitating factors and barriers to discussion are described. Skills improve over time but can be taught.

This sample of doctors describe discussion of spirituality with palliative care patients as a delicate process which needs to be aware of individual patient needs, but which can improve job satisfaction and patient care. Results of this qualitative study suggest that introduction of training in spiritual discussion into palliative medicine teaching programmes would promote development of proficiency and improve patient care.

**Abstract number:** P2-377

**Abstract type:** Poster

## Hospice Philosophy in Practice – Spiritual Care in a Hospice Setting

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Spiritual care is today seen as an integral part of palliative care within the Danish National Health Service. From international research we know hospice practitioners find it difficult to articulate the nature of spiritual care related to dying persons, especially in the hospice setting, spiritual care is nevertheless regarded as highly important to palliative care. In Denmark we do not have much research on spiritual care and as Denmark is known as a rather secular society the question about the nature of spiritual care is important to clarify. The aim of this study is to explore a practice-based understanding of the nature of spiritual care as seen from the perspective of nurses working within a Danish hospice setting. A secondary aim is to place this understanding within the secular, individualised society of a contemporary Western European Culture.

The method used in this research is phenomenological and hermeneutic and utilises philosophical practice as a tool for enabling hospice nurses to articulate and reflect upon their experiences of delivering spiritual care to dying persons. Existential philosophy and thanatological theory is used as an analytical framework.

**Results:** The nurses tend to look retrospectively to meaningful aspects of their patients' lives

more than gazing towards the possibility of a hope for an afterlife. Spiritual care is also associated with the concept of 'hope' which is itself complex and has ethical, aesthetic and metaphysical dimensions commonly expressed in terms of 'love', 'pleasure' and 'faith' all of which are rendered significant in terms of the lives of the patients.

The nurses identified good spiritual care with perceptive and attentive care because what counts as 'spiritual' for a particular patient is very individual to them.

Concluding spiritual care appears as a broad and challenging concept which requires us to ask: what is the difference between spiritual care and 'care'?

**Abstract number:** P2-378

**Abstract type:** Poster

## Sacred Music and Spiritual Well-being of Bereaved Family: A Randomized Clinical Trial

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**Aim:** Evaluate the effect of passive listening of sacred music in the levels of spiritual well-being of bereaved family.

**Methods:** Randomised clinical trial conducted at home of bereaved family registered in the Women's Network of Cancer Combat from Maringá, Brazil. Thirty families, bereaved from 1 to 12 months were randomly allocated to, group 1: experimental with sung music (n=10), group 2: experimental with instrumental music (n=10), or group 3: control (n=10).

In the experimental groups four musical sessions were performed lasting 20 minutes each, one session a week. The Spiritual Well-Being Scale (SWBS) was used to measuring and evaluating spirituality before and after the intervention. In the control group, the SWBS was applied twice, with an interval of one month. The songs 'Your presence makes living', 'Prayer for the God of life', and 'When the pain approaches', which make up the album 'Life Now and Always' from the label COMEP, were pre-selected by investigator (nurse and musician). The music delivered method was live with voice and acoustic guitar or alto recorder and acoustic guitar.

**Results:** The means and standard deviations of the scores of the SWBS, of the Religious Well-Being subscale and of the Existential Well-Being subscale before the intervention were:

101,1 (12,5), 55,4 (6,5) e 45,7 (7,3) in group 1;

99,1 (16,8), 53,2 (7,8) e 45,9 (12,1) in group 2;

102,2 (11,5), 56,2 (5,6) e 46 (7,2) in group 3.

The scores after the intervention were:

102,2 (16), 54,5(8) e 47,7 (8,7) in group 1;

107 (14,4), 55,8 (4,8) e 50,2 (12,1) in group 2;

101,4 (13,3), 56,5 (5,2) e 44,9 (10,2) in group 3.

**Conclusion:** The experimental groups showed a slight increase in the scores of the SWBS, especially in the scores of the Existential Well-Being subscale. The increase was greater in the group 2. The control group showed a slight decrease in the scores of the SWBS. The passive listening of sacred music can improve the levels of spiritual well-being of bereaved family.

**Abstract number:** P2-379

**Abstract type:** Poster

## The Church Guest Book – Landscape of Spirituality in a Danish Hospital

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**Background:** Danish spirituality is often described as individualised, privatised, secularised, and somewhat diffuse. Furthermore Danish people are described as modest in ways of expressing spirituality. Meanwhile new research find that spirituality plays an important role for a great number of people when they are diagnosed with a life threatening illness. It is therefore essential, for caregivers in palliative care, to acknowledge that patients and relatives might have thoughts regarding spirituality, and they must also be able to venture dialogue about it and thereby improve the quality of life, as described by WHO.

**Aim:** An investigation of the empirical data from 24 Church Guest Books (CGB) (4011 written messages) to find out how patients and relatives express their spirituality in the context of a Danish hospital.

**Methods:** The 4011 messages were retyped and compiled into categories in order to make a) a demographic overview of people using the CGB and b) an interpretation of the data using a hermeneutic approach, focusing on spiritual themes represented in the books; e.g. people's representations of God.

**Results:** The project discovered that as many as 1523 of the messages were written by relatives and 909 by patients.

It also reveals that people express their spirituality in very different ways some approach a distant God, others a much more personal God, and yet others a somewhat psychologised representation of God. Some people write to relatives for support. Finally a guideline on how to be church at a hospital was produced.

**Conclusion / Discussion:** The study illustrates how some patients and relatives have a need to express their spirituality, when facing illness. It also illustrates that some people need another discourse than the medical and biological focus on healing. They desire one that makes room for expressing ones feelings. This insight into the spirituality of the patients and relatives is crucial to improve the spiritual part of palliative care.

Funder CPH Parish

**Abstract number:** P2-380

**Abstract type:** Poster

## Spirituality in Palliative Care – What Are we Talking about? The Role of Clinical Pastoral Care in Promoting a Better Interdisciplinary Understanding of Spirituality in Palliative Care

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**Background:** Caring for patients' spiritual needs is considered a central part of the provision of palliative care (PC) and therefore concerns the work of all PC professions. However, the term 'spirituality' remains unclear or even controversial within the interdisciplinary practice of PC as well as within the scientific discourse.

**Aim:** To conduct a literature review regarding the question: is there a common interdisciplinary understanding of the term 'spirituality'? In detail: a) How is 'spirituality' defined in PC literature in general? and b) How is 'spirituality' defined in German clinical pastoral care literature?

**Methods:** Papers were obtained from searches a) of Medline and PsycINFO (2003–2013) and b) of Protestant concepts of clinical pastoral care in Germany using for both searches the search terms 'spiritual and palliative', 'spiritual and cancer' as well as 'spiritual and end-of-life'. More than 4000 publication titles contained the word 'spirituality'; 56 were included.

**Results:** A clear definition of 'spirituality' that is shared by all professions involved in PC could not be identified – neither in the general PC literature nor in the clinical pastoral care literature. The most frequently listed elements of spirituality were: 'meaning and purpose', 'connectedness' and 'something transcendent'.

**Conclusion:** A consensual use of the term 'spirituality' is required in order to achieve an adequately individual and beneficial assessment of patients' spiritual needs. As 'spirituality' is a concept in flux, only snap-shots are possible. Finding a common and contemporary concept of 'spirituality' needs to be a collaborative and ongoing process. The role of pastoral care in this process should be to offer a Christian definition of spirituality and to initiate and maintain an open and self-reflective interdisciplinary discussion on 'spirituality'.

**Abstract number:** P2-381

**Abstract type:** Poster

### Evaluation of a Spiritual Care Curriculum for Hospice Volunteers

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**Background:** The spiritual care (SC) curriculum content was arranged based on a discussion with hospice coordinators and available literature. Eleven themes were included in the curriculum draft. Training aims and methods for each theme were specified in detail.

**Aim:** The aim of this study was to test the practicability of the curriculum designed to teach spirituality and SC for hospice volunteers.

**Methods:** 21 participants were trained using the curriculum draft. During the two day training the participants were asked to evaluate the training aims, content, and provide feedback on curriculum's feasibility. The SPSS 21 was used to analyse the quantitative data. The thematic content analysis was used to arrange the feedback.

**Results:** The curriculum was estimated to be able to prepare hospice volunteers for their duty (mean=3.6; range 1–5; sd=0.676). It was also seen to be helpful for educationalists to arrange a training programme (mean=3.9; range 1–5; sd=0.964). Following themes became ranked as top content: firstly, spirituality: spiritual needs, distress, promises and resources; secondly, spiritual care: presence and communication; and thirdly, spiritual care: staying put and holding up. Detailed comments were received regarding the training aims and themes for each section. The results indicated that the selection of teaching methods needs significant improvement.

**Conclusion:** The final curriculum will assist hospice home care services to create an end-of-life care training for volunteers that integrates spirituality and SC in an agreement with their institutional agenda. For educationalists the curriculum may serve as a detailed mandate or a guideline.

## Social care and social work

**Abstract number:** P2-382

**Abstract type:** Poster

### 'A Museum with you'. Pictures from Movies in a Hospice

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A professor of history of cinema was admitted and died in our hospice in spring 2014. In his long career he collaborated with the National Museum of Cinema of our city and published several books and manuscripts on this topic. During his stay in the ward he actively collaborated with this institution moving his office into the hospice. Due to his determination and the quality of care received he could actively work until the last days of his life. In his will he desired to have a permanent exposition of pictures from notorious movies to be shown in our hospice ward.

The exposed picture are mostly from Italian famous movies from the sets. They were selected by the patient together with the hospice personnel excluding excessive joyous scenes or those with nude actors or too sad to be displayed.

The pictures are nice and pleasant and are showing a deep evocative impact on our admitted patients and their relatives. They work as a relational bridge between the guests and the professionals helping in breaking the barriers and inducing narrative.

Using an observational and narrative approach this positive and meaningful impact was studied by the staff. Themes like 'remembering and sharing positive images from the past', 'allowing emotions breathing spaces that move the death and dying away for a moment', 'highlight the whole personal history of the patient and not only the final phase' emerge from this study. As a preliminary result we conclude that this experience is helping both patients, their families and the hospice staff in easing difficult relationships and maintain alive and full of meaning the end of life experience of the patient who made this possible.

**Abstract number:** P2-383

**Abstract type:** Poster

### Professional Competencies of Social Workers in Palliative Care Specialized Services – The Romanian Experience

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**Background:** In Romania defining the competencies for Social workers (SW) in palliative care has gained recently interest due to participation in the EAPC SW taskforce. In 2012 translation of Canadian Competencies in Palliative care (PC) and adaptation to Romanian context by an expert panel established the Romanian competencies for SW in PC. 6 domains were defined: advocacy, patient and family support, research and education, information exchange, interdisciplinary team and self reflective practice covering 10 competencies.

**Aim:** To determine beneficiaries perspective on importance of the competencies in the 2 domains target on them: advocacy and patient and family support (with 4 sub-areas of expertise: situation assessment, decision making, care planning, provision of resources).

**Method:** Patients survey (outpatients and day care PC services) using a purposely designed self administered questionnaire, with 21 questions with answers on a Likert scale, July–August 2014.

**Results:** Out of 69 questionnaire distributed, 61 completed questionnaire returned (RR=88.4). Respondents were predominant women 77%, from urban area 82%, with over a year of care in the hospice 70.5%, main age group 44–65 years 54.1%. In 'advocacy' domain: 96.7% appreciated as extremely important for the SW to demonstrate the capacity to support and promote the patient's and family's case. In 'support for the patient and family' domain: 95% saw extremely important for the SW to demonstrate the capacity to accurately assess the general situation of the patient and the family; 73.7% for the SW to be pro-active and time-efficient in 'decision making'; 44.2% for the SW to demonstrate the ability of 'planning the care'; 55.7% for the SW to effectively intervene in 'providing resources'.

**Conclusions:** The patient and the family are relying on the social worker for representation, global assessment, support in finding solutions, counseling, advice and guidance.

**Abstract number:** P2-384

**Abstract type:** Poster

### Social Needs for Adult Patients with Cancer

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**Background:** Palliative Care includes holistic care, addressing needs in all four domains: physical, emotional, social and spiritual. In resource poor settings, social needs, especially financial needs, can be overwhelming and social workers roles are shaped by these needs.

**Aims:** To identify social care needs of patients with cancer who are enrolled in a hospice program. **Method:** Research in two stages: first semi-structured interviews with patients in hospice care to develop themes for the questionnaire, second a cross sectional survey of hospice patients with the special developed questionnaire.

**Results:** 12 hospice patients (5 women, 7 men) with performance status ECOG 1–2, 2–2, 3–8 were interviewed. Themes identified were: impact of the disease, symptom burden, information concerning the disease, work and illness, financial impact, changes in relationships, most difficult moments in disease trajectory, relationship with God and church. Build on the results a survey with 70 questions was designed. Survey: 323 patients responded to the questionnaire (out of 400, RR= 81,25%). Respondents were women 177 (54,8%), men 142 (44%), urban 249 (77,1%), rural 55 (18,3%). 42.5% of respondents were the main financial supporters of the family. Income was insufficient to provide medication in the case 53.3% of respondents, for basic needs like food in 44.6% cases or home maintenance payments 55.7%. 34.6% received financial support from different sources. In networking sphere 86.6% of cases had good relationships with family and 12% had problems in the relationship family. 66.1% received emotional support from family.

**Conclusions:** Social workers are indispensable in evaluation and intervention for cancer patients in hospice care to enact additional social benefits for beneficiaries, to provide comfort, financial security and hence the quality of life of patients with incurable diseases.



## Psychology and psychiatry

**Abstract number:** P2-385

**Abstract type:** Poster

### Perceptions of the Mother's Role, Spouse's Role, Parent-child Relationship & Opposite Sex Relationship in Breast Cancer Women with Mastectomy and Healthy Women

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**Purpose:** The purpose of this study was to compare the perceptions of mother role, spouse role, parent-child relationship and opposite sex relationship in breast cancer women with mastectomy and healthy women.

**Method:** In this qualitative study 26 breast cancer women with mastectomy who referred to Shohada-e-Tajrish hospital were chosen from available samples and they were compared to 26 healthy women by using the Apperception Test which constructed by researcher.

**Findings:** In positive perceptions of mother's role, spouse's role and opposite sex relationship and negative perception of mother's role, spouse's role and vague perception of mother's role, Spouse's role and opposite sex relationship existed a significant difference in the two groups.

**Conclusion:** The Qualitative analysis of 520 short stories showed, in perception of mother role, women with mastectomy were more emotionally involved with their children, they also had higher intellectual concerns about their children and had supportive role towards their children, in perception of spouse's role, physical weakness to perform the role of a wife, and the decline in intimate marital relationships were a clear cut reason for the decrease in quality of marital intimate relationship, fear of losing their spouse and families tearing apart. In parent-child relationship two different aspects of relationship was seen; one was a dependant relationship and the other one was a relationship based on exclusion of children for not being dependant which was seen in women with mastectomy. In terms of the relationship with the opposite sex, there were changes in sexual orientation, steering away and getting into a relationship with the opposite sex especially for women with mastectomy, who were either divorcee, widowed or single.

**Keywords:** Breast Cancer, Mastectomy, Perception, Mother Role, Spouse's Role, Parent-Child Relationship, Opposite Sex Relationship.

**Abstract number:** P2-386

**Abstract type:** Poster

### Predictive Factors Influencing the Illness Perception and Quality of Life in Iranian Breast Cancer Patients

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Illness perception (IP) and quality of life (QoL) are two important issues considering the breast cancer management. An attempt was made to examine the predictive variables influencing the illness perception and their impacts on quality of life in cancer patients. The key predictors adapted from some previous studies such as life satisfaction, perceived social support, self-esteem, hope, optimism, and spiritual well being were taken into account. We found out the direct or indirect effect(s) and also their magnitude on IP & QoL. Our sample included 200 female volunteers suffering from breast cancer applying exclusion criteria. The data was collected via various questionnaires. The obtained data was statistically analysed by means of path analysis & structural equation modeling.

The results revealed, of the six predictors, the spiritual well being and social support had direct effects on QoL and IP respectively. The only path has significant indirect correlation with IP was social support. Spiritual well being has the second significant direct effect on IP. Self-esteem has the third rank in both direct effects on QoL and IP.

In conclusion, here in Iran and maybe in other religious communities, spiritual intervention is an effective strategy for raising quality of life and also, social support helps women suffering from breast cancer experience better understanding and coping strategies.

**Abstract number:** P2-387

**Abstract type:** Poster

### Clinical Interventions Regarding Meaning in Life for Patients with Advanced Disease: A Systematic Review

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**Background:** Research shows that the presence of meaning in life (MiL) improves both spiritual wellbeing (SWB) and quality of life (QoL) in patients with advanced disease. Although several interventions for improving MiL have been described, a critical synthesis in order to compare them has yet to be conducted.

**Aims:** To carry out a systematic review of the literature on interventions for promoting MiL among end-of-life patients.

**Methods:** A systematic review and synthesis was conducted in accordance with the Realist and Meta-narrative Evidence Synthesis (RAMESES) protocol. The selected studies were evaluated using the CASP and the CONSORT statement.

**Results:** The search strategy retrieved 1229 articles, of which 12 fulfilled the inclusion criteria. These 12 papers described 9 different interventions, 6 of which were accompanied by an evaluation of outcome measures (see table below).

Year	Year/Author	Intervention	Main improved outcomes
1975, 1977	Zuehlke TE Watkins JT	Psychotherapy	Death anxiety and purpose in life scores
2010	Breitbart W	Meaning-Centred Group Psychotherapy	SWB total score MiL and Purpose subscale Optimism (No improvements for anxiety and depression, nor for hopelessness or desire for death)
2010	Henry M	Meaning-Making Intervention	SWB total and QoL score (No differences in psychological distress)
2012	Breitbart W	Individual Meaning-Centred Psychotherapy	SWB and QoL (No changes in hopelessness, anxiety or depression) (No differences in SWB at two months post-intervention)
2012	Mok E	MiL Intervention	QoL total score and the mean of the Existential Distress subscale

[Table 1]

**Conclusion:** Despite the growing interest in MiL interventions as part of end-of-life care there is limited empirical evidence regarding their effectiveness. Studies that have examined the possible benefits tend to measure related outcomes (such as SWB and QoL) rather than use specific instruments to assess MiL.

**Abstract number:** P2-388

**Abstract type:** Poster

### Prevalence of Delirium in Hospitalized Patients in a Palliative Care Unit

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**Introduction:** Delirium is a common neuropsychiatric syndrome in patients who are in palliative care units. The palliative care patient's increases vulnerability by having a serious illness and advanced, polypharmacy, among others. The diagnosis is clinical and can be undiagnosed as easily, confused with other conditions attributable to the underlying disease and drug effects. In the literature there are reports on the prevalence in palliative care units, ranging from 28 to 48% at the time of admission and up to 90% in the last days of life. This frequency is unknown in the population of our palliative care unit.

**Objective:** Determine the prevalence of delirium in the Oncological Palliative Care Unit.

**Methods:** 66 patients at the time of hospital admission were evaluated in the Palliative Care Unit of the National Cancer Institute by CAM (Confusion Assessment Method) and registering its main socio-demographic data.

**Results:** We evaluated 66 patients, of whom 36 (54.5%) were female; the average age was 50.22 years (SD 18.99). Of all patients, 23 (38.3%) met diagnostic criteria for delirium; of these 56.5% were hypoactive, hyperactive 4.3% and 39.1% mixed.

**Conclusions:** The population in our palliative care unit behaves in the range reported in the literature, with 38.3% of the population with delirium and hypoactive type is more prevalent.

**Abstract number:** P2-389

**Abstract type:** Poster

### The Role of Psychologists for Prevention Syndrome Professional Burnout of Hospice Workers

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**Introduction:** A characteristic feature of palliative care establishments is hard work. Highly qualified medical professionals may not always be good hospice workers. Qualifications and professional skills must be on par with the ability to empathise. In addition, there is a dissonance between time spent at work and the self-energy end result. Such constant intense physical and psycho-emotional cost creates prerequisites for the development of burnout syndrome.

**Purpose:** Show the role of the psychologist and opportunities to create a collective of professional burnout syndrome prevention.

**Methods:** Psychologist observed for 29 medical workers in Ivano-Frankivsk Hospice and the dynamics of the team, carried an analysis of interpersonal relationships and communication with patients and analysis of the various claims and causes of dismissal from work.

**The main results:** Ivano-Frankivsk hospice has The Collective System of prevention of professional burnout syndrome, which is used in different ways:

1. Personal psychological characteristics are taken into account during the hiring.
2. All employees adhere to provisions about the conservation status and psychological comfort.
3. Conducted training on personal emotional stability and self-regulation skills.
4. We use a variety of adaptive capacity microclimate group: discussion and sharing individual problem solving, Room psychological relief, optimisation of conditions and the nature of work processes, an informal team meetings.
5. Psychologist conducts regular monitoring and analysis of the physical and mental state of the staff.

**Conclusion:** There is now a huge most important resource in Hospice – a team of people with special composition of the soul and persistent opinions in mercy to patients, and support each other in solving problems.

**Abstract number:** P2-390  
**Abstract type:** Poster

## Psychological Distress in a Hospice In-patient Unit

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**Background:** Psychological distress in patients receiving palliative care is under-recognised and under-treated. Health care professionals are poor at detecting distress, and patients are sometimes reluctant to disclose psychological concerns unless a standardised questionnaire or systematic questioning is used.

**Aims:** To assess the levels and sources of distress reported by a population of patients receiving specialist palliative care in a hospice In-Patient Unit (IPU), and to assess the prevalence of likely psychological morbidity (anxiety and depression) among this patient population, using standardised assessment tools.

**Methods:** Upon admission to the IPU every patient meeting the inclusion criteria was given the opportunity to complete the Distress Thermometer (DT) and Problem List (PL), and the Hospital Anxiety and Depression Scale (HADS). Medical and demographic information was also recorded.

**Results:** Data was collected for 44 patients admitted over a two month period. 52% of patients were male, 88% had malignant disease and 11% were admitted primarily for terminal care. 41% of patients were able to complete both the DT and HADS, and 59% were either not offered (did not meet the eligibility criteria) or were unable to complete the questionnaires. Of those patients who completed the assessments, 83% scored 4 or above on the DT, and endorsed sources of distress including worry, loss of interest, sadness and fatigue. 61% and 75% of patients scored 8 or above for HADS anxiety and HADS depression scales respectively.

**Conclusions:** The prevalence of possible anxiety or depression reported here is high. Since patients nearing death often experience distress that is not well characterised by the traditional conceptualisations of anxiety and depression, there is a need to consider broader psychological dimensions of suffering. The DT may be useful for identifying broader sources of distress which may benefit from intervention.

**Abstract number:** P2-391  
**Abstract type:** Poster

## 'I Searched for Unconditional Love for my Whole Life!' Relationships of Palliative Patients – Attachment Strategies, Interpersonal Impact (II) and Social Correspondence (SC)

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**Background:** In times of vulnerability experiencing SC leads to feelings of protection and calmness. Based on II, people receive supportive or distancing resonance. Early attachment experience lead to strategies (*secure* vs. *insecure*) to secure SC. Confrontation with the own death causes distress which triggers these strategies. We attempt to bridge a gap between attachment needs and attachment oriented support for palliative patients by analysing II as mediator between attachment strategies and quality of SC.

**Method:** 5 secure und 3 insecure attached patients were included from a palliative care unit. II was measured with the Impact Message Inventory and SC was rated by a systemic psychologist after a stay of 10 days.

**Results:**

**Secure patients'** communication with family was mutual and frankly. The illness was referred to with appropriate emotions. Patients seemed open, attentive and cooperative: problem-solving strategies for terminal phase could be developed. II was friendly-dominant or friendly. Quality of SC was stable and strong.

**Insecure patients** could be divided into 2 groups: *avoidant patients* neglected to acknowledge own needs. They seemed rational busy not talking about feelings. Ambivalent patients displayed extensive need for closeness and could hardly satisfy their attachment needs. Both appeared distant and inhibited in interpersonal contact. Support offer was not noticed (hostile/distant-submissive) or perceived as patronising continuously demanding other offers (hostile/distant-dominant). Relatives were not aware and did not address the needs of the patient. None of the interaction was mutual supportive and often accompanied by psychological distress.

**Discussion:** Secure and insecure attached patients differ in their II and the quality of SC. Training for health professionals could help to sensitise for specific attachment strategies to reduce psychological distress and enhance quality of life in terminal phase especially for insecure attached patients.

**Abstract number:** P2-392  
**Abstract type:** Poster

## The Need for Social Contact during the Dying

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**Background:** The social contact need and its saturation during five stages of dying by E. Kübler-Ross stage model is mentioned only in general in the professional literature. The goal of research has been set as follows: to discover how the patient's needs of social contact are changing during the particular stages of dying in terms of the Maslow's hierarchy of needs concept.

**Methods:** The survey has been taken over the medicare staff in the hospices (121) and in the hospital facilities specialised for long-term ill patients (94). Two research questions have been posed and a questionnaire of 30 relevant questions have been completed.

**Results:** The total of 215 a questionnaire have been collected. The data have been consired from both facilities as the whole and by parts as well. The answers from both facility types seem to be fully comparable. More significant differences between two data samples have been commented. The differences are caused by the different medicare approach in considered medicare facility types. On the basis of the computed results and chi-squared tests it have been stated that there is the statistically significant dependence between the stages of dying by E. Kübler-Ross, patient's needs of social contact and its fulfillment; and a hierarchy of the individual patient's needs by A. H. Maslow.

**Conclusions:** Taking in account above mentioned results of quantitative and qualitative aspects concerning the social contact needs of the dying patient the conclusion has been made, that the social contact needs in various stages of dying by E. Kübler-Ross differ and that there is a dependence between the patient's needs in terms of the Maslow's hierarchy of needs and the stage of illness. We have discovered that the needs of social contact are highly accentuated in the terminal stage of illness.

**Abstract number:** P2-393  
**Abstract type:** Poster

## Utilization of a Needs-based Psychological Intervention in Specialized Palliative Care (SPC). Preliminary Results from the Intervention Arm in a Randomized Controlled Trial

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**Background:** The utilisation of psychological interventions among patients with cancer and their caregivers in palliative care is scarcely studied. Planning of targeted care would benefit from evidence on determinants of the utilisation of psychological interventions.

**Aims:** This study investigates the characteristics of patients and caregivers utilising a needs-based psychological intervention in a randomised controlled trial (RCT) of SPC and how they relate to the frequency of sessions received.

**Methods:** Data stem from patients in the intervention arm in an RCT of SPC at home. Data include number of psychological needs assessments and intervention sessions received, and characteristics of patients and caregivers (age, diagnosis, time since diagnosis, patient-caregiver relationship). The study is ongoing, and results will include associations with quality of life (EORTC-QLQ-C30&SF-36), distress (SCL-92), and caregiver burden (Zarit Burden Interview).

**Results:** To date, 18 patients (mean age 68) who received the psychological intervention have died after a mean of 3 months (range 0.8–9.5) in the RCT. Of 14 participating caregivers (mean age 66), twelve were spouses, one a sibling, and one a close friend. Patients were diagnosed on average 17 months (range 2–76) before inclusion, with lung (n=7), gastrointestinal (n=4), gynecological (n=3), brain (n=2), and other (n=2) tumors. Patients and caregivers received an average of 1.4 intervention sessions per month (total range 1–9), as well as a psychological needs assessment on average every 2.5 months, and 10 of 14 caregivers received one or two sessions during bereavement.

**Discussion:** This study sheds light on the utilisation of psychological intervention in palliative care and patient and caregiver characteristics that may predict utilisation. The findings can aid in planning and implementing future needs-based psychological services. *The study is supported by the Danish Cancer Society and the Tryg foundation.*

**Abstract number:** P2-394

**Abstract type:** Poster

## Negative Emotions as Predictors of Cancer Patients' Functioning

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**Background:** Contemporary medicine, and especially oncology attaches great importance to the effectiveness of therapy and good symptom control. Despite many observations suggesting a link between the emotional state of the patient and the quality of life, the care for the mental well-being of the patient is unfortunately often marginalised.

**Aim of the study:** The aim of the present study was to assess the impact of negative emotions (anxiety, depression) on the of physical, cognitive, emotional and social functioning of patients with cancer.

**Material and methods:** The study included 50 women and 72 men (mean age 57 years) with a diagnosis of cancer, suffering from cancer pain for at least three months and treated at the pain care clinic in oncology hospital. Patients' functioning was measured using Quality of Life Questionnaire (QLQ-C30). Anxiety and depression were measured using Modified Hospital Anxiety and Depression Scale (HADS-M). The results were statistically analysed. The relations were evaluated using the tau-b Kendall correlation coefficient.

**Results:** The results show that the lower the severity of depression and anxiety, the better patients' functioning in all measured areas (physical, roles, emotional, cognitive and social) was reported. Anxiety proved to be the stronger determinant of patients' functioning with the correlation coefficient of -0.324, -0.234, -0.493, -0.480, -0.425).

**Conclusions:** The results indicate that minimisation of negative emotions, especially anxiety, improved their physical, emotional and social functioning both. It shows that it is important to provide psychosocial support together with medical treatment at each stage of the disease to ensure the highest possible quality of life.

**Funding:** The study was funded with Institute's research budget.

**Abstract number:** P2-395

**Abstract type:** Poster

## Successful Use of Dexmedetomidine Continuous Subcutaneous Infusion (CSCI) to Prevent Terminal Sedation in a Severely Depressed Person

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**Background:** Patients suffering of a severe psychiatric disorder can experience a dramatic confusional, fearful, obsessional state when the dying process starts and become unable to take regular antidepressant and antipsychotic oral medication.

Dexmedetomidine, an  $\alpha_2$  adrenergic agonist, used for sedation and analgesia, allows a 'conscious sedation' and blocks the 'sympathetic storm' arising in stressful situations.

**Aims:** The aim of this case report is to assess whether continuous subcutaneous infusion (CSCI) of Dexmedetomidine could be safely and effectively used to support a patient in severe existential distress facing death.

**Methods:** Noted were:

- Diagnosis at referral
- Preexisting antidepressive, antipsychotic, anxiolytic drugs
- Other current medication
- Follow up
- Outcome

Special attention was given to the skin site.

**Results:** A 73 year old lady, diagnosed 15 months previously of metastatic lung cancer, was admitted to an inpatient palliative care unit in severe existential distress 12 days before she died. She was treated for a long standing bipolar depression with a daily dose of Lithium 800 mg, Venlafaxine 225 mg, Trazodone 150 mg. She was also on Flupentixol 20 mg 3 weekly injection, Haloperidol 2.5 mg nocte + 1 mg PRN, Clonazepam 0.5 mg PRN.

Dexmedetomidine was started as a CSCI 9 days before the died at a dose of 300  $\mu$ g/24 h, increased next day to 400  $\mu$ g/24 h (0.3  $\mu$ g/kg per h). No significant change noted in blood pressure or heart rate. The subcutaneous access remained intact for the 9 days without any local irritation.

Although the patient required additional breakthrough doses of midazolam + phenobarbital she experienced increasing periods where she was restful, more orientated and could share very meaningful moments with family.

**Conclusion:** The patient's aim was to find peace after a life-long struggle with depression and conflictual situations with family. She achieved to find this peace and share it with her family.

**Abstract number:** P2-396

**Abstract type:** Poster

## 'Rémanence': Portraits in Palliative Care

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**Aims:** To offer to patients a representation of themselves distinct from the one associated with the disease.

**Methods:** Patients' photographic studio portraits were taken in palliative care units (using make-up, lighting, and photo editing). A paper print and a digital medium were handed over to the patients. Their 'feelings' were collected after handing them over the final portraits. 9 patients took part to 4 sessions.

**Results:** For most of them, the experience was a good one. It helped some of them to retrieve a positive representation of themselves as 'before the disease'. As a result they wished to share these pictures with their family.

One person was disturbed by her evolution (cachexia). A supervision by a psychologist

seemed therefore to be necessary.

We do know that two portraits were used during the funeral, but we didn't ask anybody to describe their feelings about that.

**Discussion:** Contemporary communications techniques force upon us using representation criteria close to perfection.

Where has the patient to stand in relation to his disease? Is the horror aroused by the view of a tumor enough to prevent smoking cigarettes?

Is it acceptable to take pictures of patients in a palliative care unit? Would it be more decent to use this approach just for 'curative' patients? The aesthetic approach cannot be considered as invasive as the use of a scalpel blade but raises the question of voyeurism. Preventing ourselves from taking portraits comes to stigmatising patients. We can't help thinking of caregivers being unconsciously affected by various symbolic representations (pathology, medical imaging, and biology).

In a world in which the self-image is used for social integration these portraits allow patients to see themselves from a different viewpoint. The cameras capture pictures to keep them in our memory.

This work contributes to self-esteem. It completes the healthcare process and makes it more creative.

**Abstract number:** P2-397

**Abstract type:** Poster

## Need for Psycho-oncological-Social-care of Oncological Inpatients: A Pilot Survey Using Hornheider Questionnaires

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**Aim and object:** The aim of this survey was to identify psycho-oncological and psycho-social need in the routine inpatient care of oncological patients.

**Material and methods:** A total of 200 oncological inpatients patients underwent the paper-based Hornheider questionnaire, a validated instrument to identify the need of psycho-oncological and psycho-social care at first contact. Hornheider scores  $\geq 4$  were considered to indicate psycho-oncological and psycho-social need.

**Results:** Overall, 149 patients returned complete questionnaires (75%; 68 women and 81 men, 74  $\geq 65$  years and 75 < 65 years). Hornheider scores were  $\geq 4$ , indicating psycho-oncological and psycho-social in 49 patients, i.e. in 32.9%. Psycho-oncological and psycho-social need did not differ significantly between women and men (30.9% vs. 34.6%;  $p = 0.715$ ) but was significantly higher in patients < 65 years than in those  $\geq 65$  years (41.3% vs. 24.3%;  $p = 0.027$ ).

**Discussion:** The results of this pilot project show that almost a third of oncological inpatients are in need of psycho-oncological and psycho-social support. This in particular holds true for older patients.

## Research methodology

**Abstract number:** P2-398

**Abstract type:** Poster

## Status on the DOMUS Study: A Randomized Clinical Trial of Accelerated Transition from Oncological Treatment to Palliative Care at Home

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**Background:** Specialised Palliative Care (SPC) focuses on improving care for patients with incurable diseases and their families, which includes the opportunity to make their own choice of place of care and ultimately place of death.

**Aim:** The DOMUS study investigates whether an accelerated transition from oncological treatment to SPC enriched a psychological intervention at home for patients with incurable cancer results in more patients reaching their preferred place of care and death.

**Method:** DOMUS is a RCT with an allocation ratio of 1:1. The planned sample size is 340 adult in- and outpatients with incurable cancer, with no or limited antineoplastic treatment options, and ECOG Performance status 2-4 at a comprehensive cancer center. Patients are randomly assigned either to:

- a) standard care plus SPC enriched with a standardised psychological intervention for patients and caregivers at home or
- b) standard care alone.

The patients are followed for six month and several symptoms, psychological and treatment variables are assessed.

**Results:** 7299 patients have been screened since June 2013 and by 1<sup>st</sup> September 2014, 78 were included (43 female and 35 male, mean age = 68 y). The majority had cancer in the respiratory, digestive, reproductive, or central nervous systems. 11 concluded (8 intervention gr., 3 control gr.), 36 deceased during the study period (17 intervention gr., 19 control gr.), seven had dropped out (2 intervention gr., 5 control gr.) and 24 are still being followed.

**Discussion:** The slow inclusion of patients has required measures to optimise study development. The main obstacles for adequate recruitment of patients are strict inclusion criteria and patients' refusal to participate. Therefore, the inclusion criterion of ECOG Performance status 2-4 has been removed, which may implicate earlier intervention and an analysis of reasons for refusal is ongoing. The changes have been reported to clinicaltrials.gov.

Funded by the Danish Cancer Society and TrygFonden.



**Abstract number:** P2-399  
**Abstract type:** Poster

## The Attitudes and Experiences of General Practitioners towards Nurse Independent Prescribing of the Clinical Nurse Specialist in Palliative Care in the Community

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**Background:** Nurse Independent Prescribing (NIP) has been reported to enhance patient care and may prove beneficial to the practice of palliative care in the community. Clinical Nurse Specialists (CNSs) are key workers in the delivery of specialist palliative care, often working autonomously and in the community setting where medical prescribing is the key responsibility of the General Practitioner (GP). However, many GPs see palliative care patients infrequently, whereas CNSs are arguably better positioned to respond quickly to the needs of these patients due to their considerable expertise and close contact with them. There is little evidence on the attitudes of GPs towards NIP in palliative care in the community, particularly in Wales.

**Aim:** The aim of the study was to interview GPs in order to explore views and experiences of NIP in palliative care. The purpose was to identify barriers, benefits and support available and as a result inform future practice.

**Method:** Semi-structured interviews exploring attitudes towards NIP were undertaken with ten GPs in a locality in Wales. The interviews were audio recorded and transcribed verbatim. Data were analysed using thematic analysis.

**Results:** Four major themes were generated from the analysis of the interviews:

- i) impact of nurse prescribing;
- ii) prescribing practices;
- iii) communication;
- iv) education.

GPs' attitudes towards NIP were positive, with advantages to patient care identified including saving CNSs' and patients' time, greater autonomy for the CNS and being of benefit to working relationships.

**Conclusions:** NIP is an evolving area of clinical practice enhancing the nursing role. The research has given insight into the supportive views of GPs. Effective collaborative working is fundamental to successful implementation of NIP in palliative care.

**Abstract number:** P2-400  
**Abstract type:** Poster

## Factors Associated with Attrition in a Multicenter Longitudinal Observational Study of Patients with Advanced Cancer

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**Background:** Attrition is a common problem in longitudinal observational studies in palliative care. Few studies have identified factors associated with patient dropout in observational studies.

**Aims:** To identify patient characteristics at enrollment associated with attrition in a longitudinal observational study.

**Methods:** Patients with advanced cancer enrolled onto a multisite longitudinal observational study in five countries (Jordan, Brazil, Chile, Korea and India) to examine the changes in symptom profile among outpatients. Follow-up assessments were planned between 2 and 5 weeks after enrollment. We compared baseline characteristics among patients who returned for follow-up visit and those who dropped out of the study.

**Results:** 744 patients with advanced cancer were enrolled. Mean age was 57 years and 47% were female. Attrition rate was 33%, with significant variation among different countries (rates between 22% and 39%;  $p=.02$ ). In univariate analysis, baseline predictors for patient attrition were the Memorial Delirium Assessment Scale (MDAS) (OR 1.23 per point,  $p<.01$ ), Karnofsky Performance Status (KPS) (OR 1.55 per 10 point decrease,  $p<.01$ ), Edmonton Symptom Assessment Scale (ESAS) total physical symptoms (OR 1.03 per point,  $p<.01$ ), ESAS total psychological symptoms (OR 1.05 per point,  $p<.01$ ) and (log) time to referral in months (OR 0.89 per log increase,  $p=.03$ ). In multivariate analysis, independent predictors of attrition were MDAS (OR 1.1 per point,  $p=.02$ ), ESAS total physical symptoms (OR 1.02 per point,  $p=.04$ ), and KPS (OR 1.39 per 10 point decrease,  $p<.01$ ). After adjusting for baseline characteristics, there were no differences in attrition rates among participating countries. **Conclusion:** Advanced cancer patients with cognitive failure, increased physical symptoms and poorer performance status were more likely to dropout of our longitudinal observational study. These results have implications for data interpretation and future study design.

**Abstract number:** P2-401  
**Abstract type:** Poster

## How Research Governance Challenges Ethnography in Palliative Care

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**Context:** Ethnography is a key approach in medical anthropology and sociology. It seeks to untangle dense sociocultural meanings, logics and practices. Ethnographers spend long periods of time in study settings with participants and exploit a range of techniques, notably observation and interview. It is marked by a high degree of flexibility and increasingly used to study end-of-life. However, its use in such settings may be threatened by regulatory systems of ethical governance which take clinical trials or biomedical testing as the paradigm case. **Aim:** To examine the application of research governance to ethnographic research in the UK NHS. **Method:** Critical reflection on governance processes undergone in the setup of a 1 year ethnography of 'choice' for people with brain tumours. Reflection focuses on assumptions

embedded in documents required for ethical approval and their subsequent review in multiple correspondences and a meeting with a research ethics committee.

**Results:** Constructions of research, researcher, participant and risk in governance are based on assumptions derived from models of clinical trials or biomedical testing. These tend to frame research as burden, reinforce asymmetrical power relations between researcher and researched and imply a particular operation of informed consent. Fixed statements on design, instruments and implementation are required, including detailed specification of time spent with participants, full delineation of risk, and a minimum 24 hours between requests to participate and written consent.

**Conclusion:** Key assumptions embedded in governance conflict with those assumed by ethnography. This complicates how ethnographic research is practiced, risking disruption of researcher-participant relationships and extending the burden of research. This is keenly felt in palliative care settings where participants, presumed highly vulnerable, are subject to greater protection and where research relationships are key to producing quality data.

**Abstract number:** P2-402  
**Abstract type:** Poster

## End-of-Life Care Research with Bereaved Informal Caregivers – Analysis of Recruitment Strategy and Participation Rate

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**Background:** Research in end-of-life care seems to be a 'minefield' of ethical issues due to the vulnerability of the patients and caregivers. This analysis aims to enlarge knowledge on recruitment strategies and participation rates when inviting bereaved informal caregivers as participants.

**Methods:** From July 2012 and Nov 2013, informal caregivers of deceased inpatients from two German PCUs were invited to participate in a questionnaire validation study of the 'Quality of Dying and Death' (QoDD). They were called by a trained researcher earliest in the fourth week after the close one's death and latest until the 16th week. In case they refused momentarily, they were asked whether the researchers may recall at a later time point. In case of immediate consent, they took part in a planned face-to-face interview at the PCU or in their private home.

**Results:** 226 participants out of 297 eligible cases were enclosed in the study; participation rate 76.1%. The majority was female (61.1%), in middle ages (mean 55.6 years). The average time between patients' death and caregivers' interview was 57.3 days (range 26–176). The mean duration of interview was 39.1 minutes (range 10–165). The mean burden was 2.5 (range 0–10). 71.5% reported low to moderate burden (0–4) and 7.5% indicated severe burden (8–10) on a numerical rating scale.

Considering study conduction, the time point was perceived rather well chosen ( $n=13$ ), but some considered it too early ( $n=5$ ) or too late ( $n=2$ ). Coming back to the PCU was perceived rather difficult ( $n=14$ ) and some evaluated the opportunity to participated by post ( $n=1$ ), telephone ( $n=1$ ), in a couple of caregivers ( $n=1$ ) or in private home ( $n=5$ ) as valuable.

**Conclusions:** Evidence from this project shows, that ethical concerns against end-of-life research on sensitive issues with bereaved family caregivers are somehow unjustified. The method used can be recommended to other researcher and clinicians, but staffing issues have to be taken into account.

**Abstract number:** P2-403  
**Abstract type:** Poster

## Overcoming Challenges in Conducting an International Mixed Methods Study in Integrated Palliative Care

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**Background:** Conducting an international, mixed methods study in integrated palliative care (IPC) demands that many challenges are well prepared for. These include differences in national ethics regulations, language and cultural contexts and ensuring uniformity of study procedures that are responsive to local practice. Agreed methods to overcome challenges in international palliative care research are absent.

**Aims:** To discuss methods used to overcome challenges faced in conducting an international mixed methods study exploring best practice in IPC in five European countries. **Methods:** We developed an action plan including uniform study protocols, questionnaires and interview guides to ensure overall consistency of data collection. An English coding book was developed to support qualitative analysis. Two training workshops were organised in between regular project meetings. Monthly Skype meetings were held to facilitate communication. A Google drive log was used to record researcher findings.

**Results:** Study protocols were adjusted to national ethics regulations and questionnaires were translated. An online database was developed according to Good Clinical Practice. Findings were iteratively incorporated into the interview guides. Study procedures were sometimes adjusted to local contexts, but the core methodology of the study protocol remained unchanged. Training workshops, Google drive log and Skype meetings were invaluable for developing a uniform understanding of the research aims. This enhanced consistency between researchers and enabled them to translate interview questions into their own cultural contexts to investigate local perspectives.

**Conclusions:** To achieve consistent and reliable results in an international IPC study, a uniform core methodology, combined with clear and frequent communication of the study aims is essential. An international platform is useful to discuss and overcome challenges faced in IPC research.

**Funding:** EU FP7 grant #335555



**Abstract number:** P2-404

**Abstract type:** Poster

## Exploring of Factors Affecting Recruitment in a Longitudinal, Multicentre, Observational Study of Key Interventions Palliative Cancer Care (KIPCC)

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**Background:** A longitudinal observational study in Romanian and Swiss (CH) cancer centres measures patients' (pts) needs for KIPCC, perceived delivery, reported outcomes and quality indicators. Data collection consists of an interactive baseline and monthly follow-up interviews for 6 months. CH recruitment rates differ from Romanian rates.

**Aim:** To systematically analyse recruitment and characteristics of un-/willing pts and understand reasons for unwillingness of pts to report their palliative care needs/outcomes relevant for understanding representativeness.

**Method:** Review of applied recruitment processes included staff training, identifying/minimising of gate keeping and unrequired staff engagement and adaptation of pts/staff communication and recruitment scope. Independent analysis of screening logs by study nurses to identify potential systematic categories (step 1). Step 2: semi-structured interviews (SSI) with a random sample of included/not included pts (20/20) and 1–2 focus groups of staff in the catchment areas.

**Results:** So far 1290 pts of 3 catchment areas of a CH tertiary cancer centre were screened. 230 pts were eligible (stage IV cancer, prognosis  $\geq 1$  month, no cognitive impairment, ECOG 1, 2 or 3). Despite all applied recruitment optimisation, 51 (22%) refused to complete the IPOS (integrated palliative outcome scale) during screening and 39 (51% of pts with completed IPOS and criteria fulfilled) refused after having received verbal study information. Reasons for refusal in step 1 were mainly related to

- a) autonomy of CH pts,
- b) high burden of symptoms/situation,
- c) unwillingness/self-perceived incapacity to deal with an emotional topic.

Collection/analysis of step 2 is ongoing.  
**Conclusion:** Despite substantial recruitment effort/improvement in CH, further research and analysis is needed to gain insight into possible systematic recruitment bias and related factors and highlight alternatives in reaching refusing pts. Funding: SNF and Romanian partners.

## Volunteering

**Abstract number:** P2-405

**Abstract type:** Poster

## Palliative Terminal Care by Specialized Volunteers in Nursing Homes

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**Background:** At the end of their lives, elderly people in nursing homes – just like anyone else – may have a need for someone with a listening ear and open heart to support them. When the social network has diminished, and staff has little time for providing personal attention, specialised volunteers can play a significant role in supporting the resident and their family carers.

**Aims:** The aim of this project was to sensitise staff to noticing the resident might die in the near future, teach them how to raise this issue and how they can be of importance to the resident 'when nothing can be done anymore', teach them how to share the care with family members and specialised volunteers, and including specialised volunteering in the nursing homes' policy and regulations.

**Methods:** A collaboration of volunteer palliative care services and nursing homes in two cities in the Netherlands, supported by national organisations for nursing homes and palliative care volunteering. The project entailed developing instruments and courses to help staff recognising and discussing end of life issues and organising informal care (family members and volunteering), developing a training course for the volunteers on dealing with dementia and working in a nursing home setting, and developing policy within the nursing homes around palliative care and collaboration with specialised volunteers.

**Results:** an atmosphere where end of life issues are much easier recognised and discussed 'care for the carers' who are more open about their own emotions and needs high satisfaction of residents and their families (8,8 on a 10-point-scale) and staff (9,8) with the support given by the volunteers

**Conclusion / lessons learned:** The collaboration between specialised volunteer palliative care services and nursing homes is of great value in enhancing the atmosphere around end of life issues and supporting residents and their families.

**Funding:** Fonds NutsOhra (NL).

**Abstract number:** P2-406

**Abstract type:** Poster

## Bridge-walking – Mapping the Activity of Palliative Care Volunteers in New South Wales

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**Background:** Palliative care volunteers regularly feature in the media and in policy documents, but little is known about their quantum, management or scope of activities in New South Wales (NSW). In 2014 a detailed study of the participation and management of volunteers in palliative care

services in NSW was undertaken for the first time.

**Aims:** The aim of the study was to map the activity of palliative care volunteers across NSW from which to develop the capacity of palliative care volunteer services and to raise public awareness of their work. This is part of a plan to develop a state-wide framework for palliative care volunteer services over the next 3 years.

**Method:** A total of 44 Volunteer Coordinators, clinicians and other health service staff were surveyed across 34 services mostly by telephone and face-to-face meetings using a 21 question survey which measured quantitative and qualitative data. The findings were published in October 2014.

**Results:** The survey found that 1,188 volunteers participated in the services with 77.4% actively involved at any given time. Volunteers are supported by 22 Volunteer Coordinator roles state-wide with an average of 54 volunteers per Volunteer Coordinator. Palliative care volunteers contribute 110,400 hours per year to their services. About 63% of services involve volunteers within community settings, and 63% within inpatient settings.

**Conclusion/discussion:** Not all services included palliative care volunteers, raising issues of equity of access for service-users.

The challenge for local health districts and policy makers is to prioritise palliative care volunteer services within their services and policy groups.

Given the emergent nature of palliative care practice there are precedents for the inclusion of palliative care volunteers and Coordinators more extensively within communities of practice at strategic, policy and operational contexts.

**Abstract number:** P2-407

**Abstract type:** Poster

## Palliative Care Teams: How to Motivate Volunteers

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**Background:** The art of adding quality to care in the last phase of life through the Volunteering is recognised by many organisations, such as Palliative Care Associations, World Health Organization. Also studies have demonstrated the job of people who humanises care of patients, families, caregivers and the personal skills, especially the communicative skills and organisational aspects.

The task force on volunteers of the European Palliative Care Association states that in some countries in Europe, volunteers have historically had a long involvement in hospice and palliative care, sometimes even started it, and will have a significant role to play in the delivery of services in the future.

**Aims:** The authors aim to identify the integration of volunteers in our teams and to find strategies to enhance the motivation and opportunities for the development of Volunteering in Palliative Care.

**Methods:** We asked about volunteers in 24 Palliative Care Teams registered in the National Association: 11 Palliative Care Units, 5 Community Support Teams, 6 Support Teams in Hospitals, 2 combined Teams.

**Results:** From the total of 24 teams, only 13 (54%) have volunteers: 9 Units, 3 Support Teams in Hospitals and 1 combined (Unit and Community Team). From those, 8 (62%) have specific education and 4 (31%) have education in thematic areas (communication, bereavement or oncology). The number of volunteers varies from 1 (3 teams) to 10 (1 team).

**Discussion:** These results ask for strategies to find more motivated volunteers, innovative organisations and education programs in Palliative Care contributing as recognised support to the well-being of patients and their families.

**Conclusion:** Due to the complexity and vulnerability of patients and the emotions of caregivers, families and the volunteers they have to deal with, Volunteering in Palliative Care calls for more reflection on personal motivation and intentions of the volunteers.

**Abstract number:** P2-408

**Abstract type:** Poster

## Ensuring the Voice of the User/Carer for Palliative Care Research

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**Background:** Public and Patient Involvement (PPI) in research has received significant attention in recent years. There are clear examples of good practice guidelines yet questions exist regarding what user involvement in research actually means. A core theme of the work of the work of a research Network was to ensure meaningful involvement of users, carers.

**Aims:** To ensure meaningful involvement of users, carers and communities in the development and delivery of palliative care research in Ireland.

**Methods:** A Forum entitled 'Voices 4 Care' was established comprised of user/carers and citizens with an interest from across the island of Ireland. Two key stages were undertaken: Phase 1: A 'think tank' event was undertaken with key stakeholders to address aspects such as role and function; membership; marketing and key messages and culture and structures for Forum.

Phase 2: A workshop was undertaken with Forum members addressing questions around public and patient involvement in research. This focused on: challenges; skills & knowledge and strategies to develop involvement in research.

**Results:** Key messages from the user/carers were: they offered a 'common sense' open perspective that would be of clear value to researchers. Secondly they possessed significant personal experience that would be rich resource for researchers. The key challenges included the need for training; issues with language and jargon and a clear need to have ongoing engagement across the project not just a tokenistic approach.

**Conclusions / lessons learned:** User/carers involvement offers significant challenges and yet benefits to not only palliative care researchers but the wider palliative care community. Strategies for recruitment, retention, learning and ongoing engagement require consideration. There are however clear benefits not only for the research community but to overall palliative care policy, practice and education.

**Abstract number:** P2-409  
**Abstract type:** Poster

### Development of a National Programme for Volunteering in Palliative Care

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**Background:** Volunteers have a unique position in palliative care (PC), by offering informal and formal support (as members of PC team). In Romania, volunteering is a new concept and the few volunteers in PC are mainly involved in administrative activities.

**Aim:** To develop volunteering at national level by creating a network of volunteers coordinators and by recruiting and training opinion leaders and clinical volunteers for PC services in minimum 40 communities.

**Method:** The project extends over two years (April 2014–April 2016) and has four stages:

1. Set up an expert group to develop curriculum for volunteers coordinators, opinion leaders and clinical volunteers in PC and to define the portrait of the volunteer in PC services.
2. Recruitment and training volunteers' coordinators and developing a national network of them
3. Recruitment and training of opinion leaders that will raise awareness about volunteering in PC
4. Recruitment and training for clinical volunteers.

**Results:** At present the first stage has been finalised; one expert group of seven members was set-up; after presenting the project several organisations expressed interest in being involved in the project as advisory group; a curricula with 68 hours was developed (48 face to face training and 20 hours of individual study) containing 21 topics (from legal aspects, operational procedures, PC volunteer profile to speaking with media, organising campaigns and how to talk about PC in community); four Polish PC services with expertise in volunteering visited during the one-week exchange visit in Poland; PC Volunteer Portrait was developed; 45 volunteers coordinator have been recruited and will go through training in May 2015.

**Conclusion:** The project was well received, activities are in time frame, education programme and materials and selection of future volunteers' coordinators was done, it seems the proper time for developing such a programme.

## Cancer

**Abstract number:** P2-410  
**Abstract type:** Poster

### Outcome after Palliative Percutaneous Transhepatic Drainage in Malignant Biliary Obstruction

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**Background:** Percutaneous Transhepatic Drainage (PTD) has traditionally been used to decrease hyperbilirubinemia in malignant biliary obstruction with the aim of symptom alleviation and prolonging life. New endoscopic methods have gradually been added as treatment options with the result that PTD nowadays often is a second choice. Still many PTDs are performed with possible benefits for some patients and possible risks for others. This study aimed to analyse the outcome of PTD in palliative care.

**Method:** Retrospective, structured, demographic journal review of 140 patients (75 male, 65 female, median age 70) receiving PTD at Linköping University hospital from September 2008 until June 2013.

**Results:** The vast majority (126/140 patients) had a remaining PTD and in 90%, there was no documented medical information to the patient about the intervention before the PTD. For 44% the hyperbilirubinemia was the initial symptom of malignancy. 56% had a previously known cancer mostly originated from the upper gastrointestinal tract. The biliary obstruction was radiological intrahepatic in 59 cases, extrahepatic in 16 and mixed in 60. The median value for bilirubin was 237 before and 103 after PTD. 34 of 126 (27%) suffered from itching before the intervention but the bilirubin level did not differ between the groups. 19/34 (56%) were relieved after the intervention. The PTD was associated with severe complications (93%), 41% had septicemia, cholangitis or wound infection, 20/126 patients (16%) died within 14 days.

**Discussion:** PTD is beneficial for some patients with malignant biliary obstruction and persistent itching but the intervention is also associated with a high risk of complications and mortality. Therefore, the indication for PTD must be individualised, and not a main stream offer to all patients who are not suitable for an endoscopic approach.

**Abstract number:** P2-411  
**Abstract type:** Poster

### What is Known about the Experience and Outcome of Cancer Treatment in People with Dementia: A Systematic Review

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**Background:** Internationally there is a growing population of elderly people. Cancer and dementia are diseases primarily of old age. An increasing number of people will experience the double challenge of living with cancer and dementia. Cancer treatment in this group is important for managing disease but also for palliating symptoms thereby aiding management of the behavioural and psychological symptoms of dementia. This is the first study to examine what is currently known about people with cancer who also have dementia.

**Aim:** To report a systematic review of the evidence base that can inform the supportive care of people with cancer who have comorbid dementia.

**Method:** Searches were conducted in MEDLINE, Cochrane and CINAHL databases for publications about people with cancer and comorbid dementia. Limits were English language; 2000 to 9/2014; adults. The search identified 1791 titles and abstracts that were assessed against eligibility criteria and 71 were selected for full-text examination by two researchers who agreed inclusion of 9 papers, extracted data independently, then conducted a content analysis presenting findings as a narrative.

**Findings:** The nine included studies were retrospective population cohort studies (n=5) record reviews (n=3) and a survey (n=1) conducted in five resource rich countries. They evidence poorer survival in people with cancer who have dementia compared to those without dementia. Contributory factors include lower referral rates to cancer services, challenges in diagnosing cancer and lower cancer treatment rates.

Unreported is patient experience of cancer services, cancer treatment or how the cancer team manage the particular needs of people with dementia.

**Conclusions:** People with dementia have cognitive and behavioural symptoms with implications for cancer diagnosis, treatment, supportive and palliative care. Further work is needed to establish guidelines for the management of cancer in people with dementia.

**Funder:** Tenovus

**Abstract number:** P2-412

**Abstract type:** Poster

### Using Erdosteine to Regulate the Tissue Response of Radiotherapy in the Intestine, an Experimental Study on Rat

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In this study erdosteine was used to regulate the tissue response of radiotherapy in the intestine. For this study, 36 Wistar Albino rats were used and divided into 4 groups (gr). In Gr C rats were sham-irradiated. Gr IR was irradiation only group. Gr ER was defined as erdosteine control group. Gr ERRT was defined erdosteine and irradiation group. RT was in the form of a anterior field at a depth of 2 cm (1 cm bolus) 1250 cGy will be applied with 6 MV photon energy. Erdosteine, 1 day prior to RT, 10 mg / kg orally was started and was continued daily for 2 weeks. The histopathological examination of the intestinal tissue sections displayed in Hematoxylin–Eosin and Masson trichrome.

	Control	RT	ER	ERRT
Total histopathological score with hematoxyline–eosin	7,38	**25,60	9	++16
**p < 0.001; compared to control group				
++p < 0.001; compared to ER group				

[Comparison of total histopathological scores]

Immunohistochemical study of 8-OHdG levels decreased in group ER and group ERRT, compared to group RT in the epithelium and muscle layer (p < 0.001). PCNA levels in the epithelium increased in the group ERRT were compared group RT (p < 0.018). PCNA levels in the muscle layer increased in group RT when compared group C (p < 0.001). Apoptotic index in the epithelium and muscle layer of the intestine significant increased in group RT when compared to group C (respectively p < 0.001 and p < 0.006). There was a significant decrement of apoptotic index in group ERRT when compared with group RT (for both tissues, p < 0.001). There was no significant differences between the groups regarding to TGF-β1 levels.

In conclusion our results suggested that erdosteine may be effectively used in radiation induced intestinal side effects. However new clinical and experimental studies with longer follow up period are needed.

**Keywords:** Erdosteine; Radiation enteritis; Histopathology; 8-OHdG; Rat.  
(This project was supported by Selcuk University Scientific Research Projects.)

**Abstract number:** P2-413

**Abstract type:** Poster

### Relationships between Spiritual Well-being and Symptoms in Advanced Cancer Patients

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**Background :** The importance of spirituality as a central component in end of life care is increasingly recognised by health care professionals.

**Aim :** The purposes of this study were:

- (1) to explore the relationships among symptom severity, spiritual well-being, desire for hastened death, and quality of life; and
- (2) to examine the mediating or moderating roles of spiritual well-being in the impacts of cancer-related symptoms on quality of life and desire for hastened death.

**Methods :** A cross-sectional study was undertaken, in which eighty five (N = 85) terminally-ill cancer patients with mixed diagnoses have been recruited and were asked to fill out the Taiwanese version M. D. Anderson Symptom Inventory (MADSI-T), the Functional Assessment of Cancer Therapy-General (FACT-G), the Functional Assessment of Chronic Illness Therapy-Spiritual Well-being (FACIT-Sp), the Beck hopelessness Scale (BHS) and the Schedule of Attitudes Toward Hastened Death (SAHD).

**Results :** The data in this study revealed that spiritual well-being demonstrates a significant, negative correlation with symptom severity (r = -.46, p < .01); symptom severity were also both correlated with patients' quality of life (r = -.54), hopelessness (r = .51, p < .01) and desire for hastened death (r = .61, p < .01). Sleep problems are most annoying to terminally-ill cancer patients. A regression analyses showed spiritual well-being was a mediator as well as a moderator between symptom severity and quality of life. Spiritual well-being was a mediator between symptom severity and desire for hastened death. After controlling for symptom severity and other confounders (age, sex, current job situation, education degree, marital status), meaning/peace domain of spiritual well-being is a more significant predictor to quality of life and desire for hastened death as compared to faith domain.

**Conclusion :** Spiritual well-being may reduce the negative impacts on quality of life and desire for hastened death caused by cancer symptoms.

**Abstract number:** P2-414

**Abstract type:** Poster

## Building Palliative Care Bridges Across Canada

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Canada is one of 24 countries with a national cancer control strategy.

**Goals of work:** The Palliative and End-of-Life Care Initiative of the Person-Centred Perspective Division aims to improve the cancer experience and quality of life of the people living with and dying from cancer.

**Approach taken:** The Division collaborates with experts, organisations and stakeholders across the country to harness the best practices and to implement this strategy coast to coast. This is accomplished through convening meetings; establishing networks; creating solutions with partners to meet shared goals; investing in and managing innovative projects; and brokering knowledge to accelerate adoption of best practices. In all the work, the patient and family perspective is an integral component and representatives participate on all our committees.

**Results:** To date we have established a National Palliative & End-of-Life Care Network that includes appointees from the Provincial Ministries of Health & Cancer Agencies; funded 5 projects that address: integration of palliative care and emergency services; integration of palliative care with the cancer system; creation of online knowledge tools; education in adult and pediatric palliative care; and established priorities for further collaboration to enhance palliative care across the country.

**Lesson learned:** Canada's cancer control strategy is an effective model to accelerate change through a multi-jurisdictional, collaborative approach that respects that health-planning and delivery is decided at the provincial level.

**Abstract number:** P2-415

**Abstract type:** Poster

## The Potential Role of Modern Radiotherapy Techniques in the Treatment of Malignant Spinal Cord Compression

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**Background:** Radiation therapy is one of the main treatment modalities for spinal cord compression (SCC). Typical palliative radiation therapy techniques have used weighted anterior-posterior (APPA) or a three field (a posterior and two lateral) technique. However, as delivery techniques have evolved dramatically over the past decades, volumetric arc therapy (VMAT) has gained wide acceptance. VMAT allows for a more conformal dose distribution, with a dose reduction in the organs at risk. Such a dose reduction may result in less toxicity. Most of the reports indicate the benefit in curatively intended treatments; however, in palliative intended treatments improved techniques also seem to be warranted.

**Aim:** To investigate the doses to the kidneys and bowel for each of the following three radiation therapy techniques for SCC: APPA, three field and VMAT.

**Methods:** For 20 patients treated with radiotherapy for SCC at our hospital, we created an APPA, a three field and a VMAT plan. The plans were treated in Eclipse (Varian Medical Systems, Palo Alto, USA). The kidneys and intestines were contoured. The mean and maximum kidney doses, and the volume of bowel which received 20 Gy, were extracted for each plan.

**Results:** VMAT lead to the most conformal distributions: the high dose areas were restricted to the target volume, while the healthy tissue, especially the bowel, received a lower dose. In contrast, the APPA plan lead to a larger volume of bowel being irradiated, while the three-field technique spared the bowel at the expense of a higher dose to the kidneys.

**Conclusion/discussion:** Patients treated for SCC in the lower thoracic or lumbar region may benefit from VMAT treatment, as it reduces considerably the dose to the bowel and kidneys compared to APPA or three-field treatments. Future studies should assess organ toxicities related to the various radiation therapy regimens in patients with malignant spinal cord compression.

**Abstract number:** P2-416

**Abstract type:** Poster

## Does Chemotherapy Improve Quality of Life in Advanced Pancreatic Cancer? A Systematic Review

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**Background:** Advanced pancreatic cancer is associated with high mortality and symptom burden. Chemotherapy has been shown to improve survival. The aim of this systematic review was to assess the effects of chemotherapy on health-related quality of life (HRQoL) and the common symptoms pain and cachexia.

**Methods:** The PubMed, Embase and Cochrane Central databases were searched. Eligible studies met the following criteria: Randomised controlled studies of chemotherapy (including targeted therapy) with n>100; locally advanced or metastatic pancreatic adenocarcinoma; HRQoL, pain and/or cachexia examined.

**Results:** 30 studies were eligible and categorised as follows: Evaluating HRQoL (n=23), pain (n=24) or cachexia outcomes (n=8). Four studies found significant differences in HRQoL between treatment arms: Gemcitabine (Gem) was superior to BAY12-9566 and the combination of Gem and marimastat; FOLFIRINOX was superior to Gem; fluorouracil (FU) and cisplatin was superior to FU. Changes in mean HRQoL scores from baseline were presented in 14 studies: Three studies reported an improvement in at least one treatment

arm, two studies a worsening and nine studies stable scores. Seven studies found significant differences in pain outcomes between treatment arms. Improvement in mean pain intensity scores from baseline was examined in eight studies and observed in seven. Cachexia was assessed as weight change, but few details were reported. No studies found significant differences favoring one treatment arm, and only a small number of patients gained weight from baseline. Of the four studies reporting a significant difference in survival between treatment arms, three reported of a corresponding difference in HRQoL and/or pain outcomes.

**Conclusion:** Chemotherapy can maintain HRQoL and improve pain control in patients with advanced pancreatic cancer. Improved survival does not come at the expense of deterioration of HRQoL or pain. Conclusions about effects on cachexia cannot be drawn.

**Abstract number:** P2-417

**Abstract type:** Poster

## General Self-efficacy as a Predictor of Psychological Adjustment of Cancer Patients

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**Background:** Theories and research results indicate that attitude toward disease that patients demonstrate is associated with the effectiveness of patients' coping with cancer and negative consequence of the disease, i.e. pain, lower well-being, and changes in life caused by disease. General self-efficacy is associated with patient's belief to being able to control their every day life and behavior.

**Aim of the study:** The aim of the present study was to assess the psychological adjustment to disease in patients treated for different types of cancer.

**Material and methods:** The study included 572 patients (348 women and 224 men, 19–91 years, M=54) diagnosed of cancer: tissue and bones, gynecology, urology, lungs, breast, lymphomas, digestive system, head and neck. General self-efficacy was measured using the General Self-Efficacy Scale (GSES). Psychological adaptation to disease was measured using the Mental Adjustment to Cancer Scale (Mini-MAC).

**Results:** The results show that there is a significant positive correlation between general self-efficacy and fighting spirit ( $r = 0.223$ ), and positive reinterpretation ( $r = 0.131$ ). There is also a significant negative correlation between general self-efficacy and helplessness-hopeless ( $r = -0.297$ ) and anxious preoccupation ( $r = -0.262$ ).

**Conclusions:** The results shows, the higher the general self-efficacy, the higher the active, constructive adjustment style and conversely – the lower the general self-efficacy, the higher the passive unconstructive adjustment style. These results indicate that psychological intervention should focus on strengthening patients' faith that there are able to take control over the many aspects of their live associated with cancer and in this way to control the disease effectively.

**Abstract number:** P2-418

**Abstract type:** Poster

## Prognostic Biomarkers in Advanced Cancer: A Multicentre Prospective Trial

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**Background:** Estimating prognosis in patients with advanced cancer is necessary to guide clinical decisions. However prognostication by clinicians is often erroneous, optimistic, informal and subjective. Clinical markers & biomarkers of the systemic inflammatory response have been validated for prognostication in advanced cancer and these have been combined in prognostic tools. A systematic review by this group has concluded that although numerous prognostic tools exist comparison of these has not been done. A prospective study examining key prognostic factors alone, and in combination as prognostic tools would enable comparison and identification of the most predictive prognostic markers in advanced cancer.

**Aims:** To assess all prognostic factors & tools, which have been shown to predict survival in advanced cancer.

**Methods:** A multicentre prospective observational study was undertaken between January 2013 & September 2014. Eligible patients met the following key criteria: > 18 years of age, advanced incurable cancer & Eastern Cooperative Oncology Group (ECOG) performance status 1–4. The following information was collected at study baseline: cancer type & stage, details of chemotherapy/ radiotherapy, drug history, co-morbidities, clinician predicted survival, Karnofsky performance status, ESAS symptom scores for dysphagia & xerostomia, presence of oedema, presence of ascites, weight loss information, body mass index, timed up & go test, two minute walk test & the EORTC QLQ-C30 questionnaire. The following biomarkers were collected: C Reactive Protein, albumin, lactate dehydrogenase and differential white cell count. Patients were followed up until death & censoring was a minimum of three months. Kaplan Meier & multivariate Cox regression models were used to compare the prognostic factors. **Results:** Approximately 500 patients were recruited. The results are being analysed and will be presented with the key prognostic tools compared.

**Abstract number:** P2-419

**Abstract type:** Poster

## The Impact of Age on End-of-Life Care for Patients Dying from Cancer: A Nation-wide Population-based Study

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**Background:** If age of cancer patients affects the quality of end-of-life (EOL) care has been insufficiently studied

**Aim:** To explore age-related differences in the quality of EOL care delivered to patients with cancer in Sweden, using a population-based approach.

**Methods:** All adult patients reported to the Swedish Register of Palliative Care to have died from cancer in 2011–2012 (N=26,976) were categorised in five age-groups: 18–39 y (G1, n=341), 40–59 y (G2, n=3017), 60–74 y (G3, n=10,126), 75–84 y (G4, n=8,393) or ≥ 85 y of age (G5, n=5,099). Odds ratios (ORs) with 95% confidence intervals were calculated using the oldest group (G5) as reference.

**Results:** Young patients were more often informed about imminent death, ORs 3.85 (G1), 2.24 (G2), 1.74 (G3), 1.4 (G4). Families of young patients were more often informed, with ORs 2.55 (G1), 1.87 (G2), 1.39 (G3), and 1.25 (G4), and more likely to be offered bereavement support, ORs 4.56 (G1), 2.33 (G2), 1.65 (G3), 1.33 (G4). External competence was more often sought in the care of young patients, ORs 4.33 (G1), 2.85 (G2), 2.07 (G3), 1.39 (G4). Parenteral fluid therapy during the last 24 hours was more common in young patients with ORs 2.61 (G1), 1.95 (G2), 1.71 (G3), 1.29 (G4). Prescriptions as needed (PRN) against anxiety or nausea were more common in young patients, with ORs 3.79 (G1), 2.69 (G2), 1.66 (G3), 1.25 (G4), and 3.63 (G1), 2.04 (G2), 1.47 (G3), 1.23 (G4), respectively. Systematic pain assessment was more common in young patients, ORs 1.61 (G1), 1.45 (G2), 1.37 (G3). Severe pain (ORs 2.5–1.1 for G1–G4), breathlessness (OR 2.27–1.1 for G1–G4) and anxiety (OR 3.74–1.2 for G1–G4) were more frequent in young patients.

**Conclusion:** Age impacts on several quality aspects of EOL care for cancer patients in Sweden. The oldest appear to be disadvantaged. Age-related differences with respect to symptoms need to be recognised.

**Funding:** The executive committee of the National Quality Registries in Sweden.

Abstract number: P2-420  
Abstract type: Poster

## Phoenix RETRO: A Retrospective Study of Chemotherapy in Palliative Intent (CPI) in Patients with Advanced Cancer with a Reduced Performance Status (PS) on an Accredited Integrated Palliative Care (PC) Unit

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**Background:** Patients with advanced cancer often suffer from a decline in physical function, which is reflected in a reduced PS. The benefit of CPI in patients with reduced PS (>2) remains undetermined although it is a common practice.

**Aims:** Our aim was to analyse in a retrospective review the current practice, experiences and outcomes of CPI in patients with PS2/3/4 at a PC unit in a tertiary cancer centre.

**Methods:** Charts of cancer patient with advanced cancer (PS2/3/4) with newly started CPI (expected tumor response rate ≤ 20%) were analysed from the years 2012–14 PC-Unit Data: Average 250 patients/year, death rate 48%, mean hospitalisation 11 days. Charts were selected based on pharmacy order forms. Variables extracted encompass patients, disease, CPI (dosing and toxicity) and outcome data, especially key interventions of palliative cancer care (KI-PCC): Symptom management, illness understanding, decision making, spiritual needs, network involvement and end of life preparation.

**Results:** Of 96 screened patients (exclusion: 12 cancer type, 28 no CPI start, 5 PS Status, 14 other) 37 were included. Mean age 65, (Min 29, Max 85) male 23, female 24, Tumor types: Lung (7), GI (9), Breast (7), GU (8), Brain (2), Sarcoma (2) Chemotherapy lines: II (12)>III (10)>I (5)>IV (3), missing (7). Most common CPI: Platin (17), Taxane (19), 5-FU (12), Gemcitabine (15), Navelbine (9). PS at CPI Start: PS 2 (11), 3 (22), 4 (4). ΔPS Admission-Discharge: 11 Improved (5 PS3, 2 PS4), 12 stable, 5 worse, 4 missing. 5 patients died on the ward. Mean hospitalisation duration: 26 days. CPI and KI-PCC variable analysis is in progress.

**Conclusion:** On this PC unit different tumors are treated with a variety of compounds. In a setting with structured KI-PCC processes and individual primary dose reduction selected patients seem to benefit from CPI, even with reduced PS (3/4). In depth analysis is in progress. The results reflect current practice in a highly debated field with limited published data.

Abstract number: P2-421  
Abstract type: Poster

## Renal Failure in Patients with Advanced Cancer Sent to Palliative Care

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It is difficult to quantify the extent of renal complications associated with malignancy because renal dysfunction may occur before to the oncology discovery, simultaneously with the diagnosis and even after the treatments used. The objective was to estimate the prevalence of renal failure in patients with advanced cancer sent to Palliative Care Service of the National Cancer Institute. Patient records outside curative cancer treatment for the first time referred to palliative care in the period July–December 2012. The glomerular filtration rate was calculated with the MDRD (Modification of Diet in Renal Disease) with 4 variables and Cockcroft–Gault, they were analysed comparatively. Were studied 380 patients, of which only 68 met the necessary for the calculation of glomerular filtration rate variables. Using both equations was observed that patients with a GFR < 60 ml / min, corresponding to carriers of any gastrointestinal cancer. With the relationship the BUN / creatinine ratio 36.7% had prerenal failure. Cancer patients have hypovolemia secondary to loss of extracellular space by reduced intake or excessive loss and bleeding. The appropriate water management of patients can slow the progression of chronic kidney disease morbidity initial slowing and therefore better quality of life for the patient.

Abstract number: P2-422  
Abstract type: Poster

## Care Needs in Cancer at the End-of-Life for Recipients Study (CaNCERS)

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**Background:** Unmet healthcare needs can have adverse consequences in patients with advanced cancer. Systematic identification of moderate or severe unmet needs is thus

important so that gaps in service provision can be highlighted and addressed. Hence, we used the 59-item Cancer Need Assessment Tool (CNAT) in a cross-sectional study to identify the unmet healthcare needs of patients with advanced cancer in Singapore.

**Methods:** Post-institutional review board approval, eligible inpatients and outpatients were enrolled. The inclusion criteria was patients diagnosed to have metastatic solid cancers no longer undergoing curative treatment with intact cognition. The CNAT was administered, with the help of an interviewer, to assess 7 domains of unmet need namely 'Information /education', 'Psychological', 'Healthcare staff', 'Physical symptoms', 'Hospital facilities/services', 'Social/spiritual support' and 'Practical support'. Unmet need was rated as nil, mild, moderate or severe.

**Results:** Altogether, 173 inpatients and outpatients with advanced cancer were surveyed. The median age of all study subjects was 60 years and an outpatient: hospitalised inpatient ratio of 1.36. Breast, colon and lung cancers were the commonest cancer types. Only 39.9% of all study subjects received palliative care at the time of the survey. Of all subject, 16.1% (n = 28) had moderate and severe overall unmet need affecting multiple domains. The highest percentage of moderate or severe scores was in the 'Information and education' domain in those with moderate or severe overall unmet need. Malay ethnicity was significantly observed to be associated with moderate or severe overall unmet need with ethnic differences in the percentage of moderate or severe scores for specific CNAT domains and items.

**Conclusion:** Significant unmet need occurs in the minority of patients with advanced cancer with Malay (minor) ethnicity as a possible risk factor in Singapore.

Abstract number: P2-423  
Abstract type: Poster

## Hope Dies Last... A Qualitative Study into the Meaning of Hope for People with Cancer in the Palliative Phase

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**Background:** Palliative patients may have strong hope, even hope for a cure, despite awareness of prognosis. This hope features prominently and positively affects their relations and quality of life. Healthcare practitioners feel uncomfortable with this hope. So far, the meaning of hope in palliative patients with cancer has hardly described and understood.

**Aim:** To explore the meaning of hope amongst patients with cancer in the palliative phase of their illness.

**Design:** A secondary analysis was made of interview data (n=80) obtained in a series of studies in the Netherlands and Flanders on living with cancer with a short life expectancy (between 3 and 12 months).

**Results:** Palliative patients may have a number of hopes at the same time. Also, they may hope (for recovery) and, at the same time, make preparations for imminent death. Hope has a function: patients hope because they cannot forsake it and because they benefit so much from it. Hope can spring from many sources and can evoke over time in reaction to the disease or as a result of influencing internal or external factors. If there are fewer potent sources to tap into, people create hope themselves, if necessary against the facts. Self-created hope takes more effort to maintain. Hope is a thought construct which is cherished, nurtured and protected against threats. Hope can vary in strength, and that strength is not determined by chances, but by need.

**Conclusions:** A better understanding of the process of hope, its dynamics, and its meaning and function will lead to better psychosocial support for palliative patients with cancer. Unrealistic hope in well-informed patients is rarely due to lack of insight into their own situation, denial or misunderstood information. Healthcare practitioners convey many messages that affect the work of hope.

Abstract number: P2-424  
Abstract type: Poster

## Contrast in Palliative Care Patients Profile Admitted for at a University Hospital versus Hospice

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**Background:** Palliative Care (PC) is a wide term that includes a wide range of patients assisted in different settings who may differ in clinical characteristics.

**Aims:** To compare differences in performance status, symptom control and medication delivery between patients assisted by a PC Consultant Team (CT) and Hospice (H).

**Methods:** We conducted a secondary analysis of the prospective data collected from the European Palliative Care Cancer Symptom study (EPCCS). Differences in performance status at inclusion (T1) and second evaluation (T2) after four weeks was measured by the Karnofsky index (KPS) (Mann–Whitney test), symptom control using the Edmonton Symptom Assessment System (ESAS-r) (Mann–Whitney test), medication delivery with a check-list specifically designed for this study (χ<sup>2</sup>).

**Results:** 50 patients were recruited by the CT and 58 in the H. CT population was composed by gastrointestinal cancer patients only, H population by lung (33%), gastrointestinal (29%), and other tumors (38%). 76% of patients had metastatic disease. Only 7% H patients were receiving chemotherapy vs. 58% of CT.

26 CT patients and 23 H patients had complete data at T2. KPS was significantly different between CT patients and HS patients at T1 –KPS median (M) 70 vs. 50 (p 0.00)-, and at T2 –KPS M 70 vs. 50 (p 0.00)-. Dyspnea was the only symptom on the ESAS-r that showed differences in both evaluations: T1 H group M 2 vs. CT 0 (p 0.00), and T2: H M 2 vs. CT 0 (p 0.001). No opioid analgesics (p 0.009; p 0.001), co-analgesics (p 0.002; p 0.003), corticosteroids (p 0.028; p 0.004), antibiotics (p 0.002; 0.047) and neuroleptics (p 0.000; p 0.003), were more prescribed in H in both evaluations. Only antiemetics were more prescribed in the CT patients (p 0.000; p 0.001). No differences in opioid prescription.

**Conclusion:** Patients assisted by a CT had better performance status. Medication prescribed in H seems to be more focused on symptom control. Symptoms were well controlled in both settings.



**Abstract number:** P2-425

**Abstract type:** Poster

## Disparities in Hospitalized Cancer Patients Receiving Palliative Care Consultation

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**Background:** Racial disparities in healthcare are documented among minority groups. As a result, minorities are diagnosed with advanced cancer and have inferior outcomes which lead to increased suffering. Little is known, however, about disparities in access to and outcomes of patients receiving specialty palliative care (PC).

**Aims:** Evaluate outcomes among hospitalised minority patients (black and Hispanic) with cancer receiving PC consultation.

**Methods:** We used data from the Palliative Care for Cancer Patients (PC4C) study, a multisite observational study of the effect of inpatient PC on patient outcomes and utilisation among cancer patients. We limited our sample to patient's receiving PC from established, interdisciplinary teams. Univariate analyses and multiple regression analyses compared differences in outcomes among minority and non-minority patients.

**Results:** 583 (19%) patients received PC. Of those, 166 (28%) were minorities and 418 (72%) non-minorities. Mean days to PC was 4.4 vs. 3.2 in non-minorities and minorities, respectively ( $p=0.65$ ). At baseline, minorities reported a higher burden of symptoms on the condensed memorial symptom assessment scale (CMSAS). Similarly, they were less likely to have discussed their wishes with their doctor ( $p=0.04$ ); less likely to have completed a living will ( $p<0.001$ ), or have a proxy ( $p<0.001$ ); had no difference in pain but were less likely to be taking pain medications ( $p<0.001$ ) or report relief from pain medicines ( $p=0.05$ ). After PC all CMSAS symptoms improved for minority patients (except worry;  $p=0.03$ ). Additionally, after PC there were no significant differences among minorities with respect to discussing wishes ( $p=0.27$ ), DNR completion ( $p=0.72$ ), proxy assignment ( $p=0.22$ ) and taking pain medications ( $p=0.22$ ) when compared to non-minorities.

**Conclusions:** PC is associated with improvements in symptom control and discussions of care goals among minority patients who have worse baseline health assessments.

**Abstract number:** P2-426

**Abstract type:** Poster

## Last Month of Life – How Often Are Patients Overtreated?

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**Background:** In the last month of life (LMoL) the goal of management shifts from curing to healing emerging symptoms which worsen the quality of life (QoL). Methods such as specific anticancer treatment (ST) are discouraged in this period as they provide no additional benefit and lead to toxic adverse effects. In 2009 we evaluated how many patients (P) were treated with ST in the LMoL. As results were not encouraging many educational events and workshops were organised in order to further educate doctors on this topic.

**Aim:** To re-evaluate the situation after three years.

**Methods:** Data from 361 P who died at our institution in 2012 was retrospectively collected and compared with results from 2009 for the rates of use of ST (chemotherapy (Cht) and target therapy (TTh)) and initiation of a new line of ST. The association between overtreatment and P' age, WHO performance status (PS) and chemosensitivity of tumour (lymphoma, small-cell lung cancer, germ cell tumours, breast, bladder, ovarian, head & neck, colorectal cancer, gastrointestinal stromal tumour) was evaluated using Chi-square test.

**Results:** Median age at the time of death was 61 years (range 22 – 87), 176 P (48,8%) were diagnosed with the chemosensitive cancers and 167 P (46,3%) were in PS 3 or 4. In the LMoL 124 P (32,7%) received ST in 2012 as compared with 110 P (39%) in 2009. In the LMoL a new line of ST was initiated in 52 P (14,4%) in 2012 and 49 P (17,5%) in 2009. We found no statistically significant association between overtreatment and age (comparing younger and older than 70 years old) ( $p=0.4$ ), chemosensitivity of the tumor ( $p=0.4$ ) or PS ( $p=0.1$ ). However P having PS 3 or 4 were statistically significant not initiated a new line of ST ( $p<0.05$ ).

**Conclusion:** We found a negligible difference in the rate of use of ST between 2009 and 2012. We need to implement further efforts in physician recognition of end-of-life period and appropriate decision making about discontinuing futile treatments.

**Abstract number:** P2-427

**Abstract type:** Poster

## Mechanisms that Contribute to the Tendency to Continue Chemotherapy in Patients with Advanced Cancer. Qualitative Observations in the Clinical Setting

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**Background:** Many patients receive aggressive treatment shortly before death, although this is often seen as unfavourable practice.

**Aim:** Describe mechanisms that contribute to the tendency to continue chemotherapy in patients with advanced cancer.

**Methods:** Qualitative observations at an outpatient oncology clinic of a university hospital. 28 patients with advanced cancer and their physicians were included.

**Results:** We uncovered four mechanisms:

- 1) 'presenting the full therapy sets the standard' patients seemed to base their justification for continuing chemotherapy on the 'standard' therapy with the maximum number of cycles as presented by the physician at the start of the treatment;
- 2) 'focus on standard evaluation moments hampers evaluation of care goals' whether or not to continue the treatment regimen with a new cycle of chemotherapy was mostly only considered at standard evaluation moments using the results from CT or MRI, and was not discussed in between these tests;
- 3) 'opening question guides towards focus on symptoms' most patients gave an update of

their physical symptoms or treatment side effects in answer to the opening question 'How are you doing?' Physicians consequently discussed how to deal with this at length, which often took up most of the visit;

4) 'treatment is perceived as the only option' patients mostly wanted to continue with chemotherapy because they did not want to give up or felt that they had to try every option the physician offered. Physicians also often seemed to focus on treatment as the only option.

**Conclusion:** The mechanisms seem to be a result of working in a routine manner combined with a lack of reflection on care goals throughout the visits. Discussing care goals more regularly with the patient, facilitated for instance by implementing early palliative care, might help counter the mechanisms and enable a more well-considered decision. This could be either stopping or continuing chemotherapy.

**Abstract number:** P2-428

**Abstract type:** Poster

## The Pelican Study: Patient Experience of Living with CANcer associated thrombosis

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**Background:** The management of cancer associated thrombosis (CAT) in the palliative setting poses many challenges to clinicians. Whilst the management of CAT is well established, its impact on the patient's quality of life (QoL) is not fully understood. Additionally, venous thromboembolism (VTE) QoL tools in current use were developed for the non-cancer population and may be of limited use in the cancer setting.

**Aim:** To evaluate the experiences of patients with CAT, to identify key unmet needs and evaluate the utility of (VTE) QoL tools in the context of the cancer journey.

**Method:** 20 patients were recruited from two hospitals in South Wales. A two part qualitative interview consisted of semi-structured interviews to explore the effect CAT has on QoL, and cognitive interviews to assess currently available QoL questionnaires and their relevance to cancer patients. Framework analysis was applied to the semi-structured interviews. Both deductive and inductive analyses were used to analyse the cognitive interviews.

**Results:** Major themes emerging from the semi structured interviews included a lack of knowledge of VTE symptoms causing a delay in patient treatment, a lack of knowledge of VTE risk with cancer and cancer treatment and a lack of information and support during and post diagnosis prior to referral to a specialised CAT clinic. VTE QoL tools were found to be inadequate since the experience of cancer and VTE are enmeshed.

**Conclusion:** More information and support is needed for both cancer patients and their health providers. QoL questionnaires specifically for use with CAT patients need developing. **Funder:** Leo Pharma, Denmark

**Abstract number:** P2-429

**Abstract type:** Poster

## Reasons for Continuous Sedation until Death in Cancer Patients: A Qualitative Interview Study

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**Purpose:** End-of-life sedation, though increasingly prevalent and widespread, remains a highly debated medical practice in the context of palliative medicine. This qualitative study aims to look more specifically at how health care workers justify their use of continuous sedation until death and which factors they report as playing a part in the decision-making process.

**Methods:** In-depth interviews were held between January 2011 and May 2012 with 28 physicians and 22 nurses of 27 cancer patients in Belgium who had received continuous sedation until death in hospitals, palliative care units or at home.

**Results:** Our findings indicate that in general physicians and nurses justify the use of continuous sedation until death by referring to the presence of a broad range of clinical indications, largely in line with existing guidelines. However, the decision to start continuous sedation is not always based on existing suffering but often on the intention to prevent further anticipated suffering. We also found a wide range of non-clinical factors influencing decision-making, such as the patient's personality, values and beliefs and the views of their relatives. Finally, our findings suggest that in some cases continuous sedation was resorted to as an alternative option at the end of life when euthanasia, a legally regulated option in Belgium, was no longer practically possible.

**Conclusions:** Medical decision-making for continuous sedation until death is not only based on clinical indications but also related to morally complex issues such as the social context and the personal characteristics and preferences of individual patient and their relatives.

Abstract number: P2-430  
Abstract type: Poster

### **Incidence of Diabetes Induced by High-dose Glucocorticoid Treatment in Cancer Patients**

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**Background:** Prolonged hyperglycaemia due to glucocorticoid therapy is a well-known – but less well-described – clinical condition. The magnitude of the risk of developing diabetes during high-dose glucocorticoid treatment is not known and monitoring for development of diabetes during treatment is random.

**Aims:** We aim to assess the incidence of glucocorticoid therapy-induced diabetes and to identify risk factors for development of diabetes in non-diabetic patients with metastatic spinal cord compression (MSCC) receiving high-dose glucocorticoid therapy during radiation therapy in order to provide guidelines for rational screening.

**Methods:** The study is a prospective, observational study of outpatients and hospitalised patients with MSCC treated with  $\geq 100$  mg prednisolone per day. Primary endpoint is development of diabetes defined by two independent measurements of capillary plasma glucose levels  $\geq 11.1$  mmol/l (WHO criteria). Secondary endpoint is diabetes needing glucose-lowering therapy – according to local guidelines – to control plasma glucose levels.

**Results:** 66 patients has been included; 36% women, age 68 (46–87) years, BMI = 25 (14–39) kg/m<sup>2</sup>, daily dose of prednisolone 276 (100–563) mg. A total of 27 of included were diagnosed with diabetes (41%; 95%CI 29–54%). Seven patients with diabetes (11%; 95%CI 4–21%) needed treatment with insulin. In the logistic regression analysis only HbA1c made a significant contribution to prediction. Odds ratio for needing insulin treatment for diabetes during prednisolone exposure increased by 1.4 (1.0–2.0) per unit (mmol/mol) HbA1c ( $p = 0.04$ ). **Conclusion:** Almost half of patients with MSCC undergoing radiation therapy and high-dose glucocorticoid therapy developed diabetes and one fourth of the diabetic patients needed insulin therapy. Only baseline HbA1c was positively associated with risk of needing antidiabetic treatment. These results underline the importance of systematic screening for glucocorticoid-induced diabetes.

Abstract number: P2-431  
Abstract type: Poster

### **Integration of Palliative Care in Patients with Cancer in Europe. Where Do we Stand and what Are the Challenges?**

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**Background:** Palliative Care (PC) aims to improve the quality of life for patients with cancer and their families and its efficacy has been empirically demonstrated by several studies. In Europe delivery of PC in patients with cancer remains suboptimal.

**Aims:** To conduct a systematic review to identify existing guidelines/pathways for integrated PC in patients with cancer and to evaluate their content.

**Design:** We included studies with adult patients with cancer and their caregivers, published between 1995 to 2013 in Europe, in English, French, German, Dutch, Hungarian or Spanish. Studies were ranked using Emanuel's framework, a tool to assess the content of integration of PC in guidelines. Studies fulfilling at least a threshold of two out of the eleven criteria were included.

**Data collection:** Two reviewers screened the search results. Cochrane, PubMed, EMBASE, CINAHL, AMED, BNI, Web of Science, NHS Evidence were searched. BMJ Palliat. Support Care, Eur. J. Palliat. Care, J. Pain Symptom Manage., J. Palliat. Med. and MED PALLIATIVA and references from included studies were hand-searched. Google was searched to achieve results from grey literature. Two reviewers screened the search results.

**Analysis:** Due to the heterogeneity of the studies, a narrative synthesis of findings is presented.

**Results:** The review included 74 out of 28,277 potentially relevant studies: 60 guidelines and 14 pathways. Of these, seven studies fulfilled at least 10/11 Emanuel's criteria. 80% of the guidelines/pathways emphasised a holistic PC approach, 64% focused on PC interventions aimed in reducing suffering and 57% did not elaborate on the referral criteria.

**Conclusion:** A holistic approach was clearly identified by most of the included studies but the referral criteria to start PC and the interventions to be used remain a contentious topic. The 7 studies that fulfilled at least 10/11 Emanuel's criteria can serve as benchmarks for describing integrated PC in guidelines.

Abstract number: P2-432  
Abstract type: Poster

### **Deconstructing Depressive Symptoms in Advanced Cancer: Is 'Sickness Behavior' a Factor?**

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**Background:** The role of inflammation in the pathophysiology of depression remains unknown. In contrast, sickness behavior is a symptom cluster that exhibits a robust relationship with inflammation. Although sickness behavior and depression share overlapping symptoms, their relationship is unclear and complicated by the presence of a medical illness.

**Aims:** The current study uses confirmatory factor analysis to examine the construct of sickness behavior in patients with advanced cancer using a standard self-report measure of depressive severity.

**Methods:** Patients ( $N = 167$ ) were recruited from chemotherapy clinics and the Department of Psychiatry at Memorial Sloan Kettering Cancer Center. Patients were administered the

Beck Inventory for Depression-II and other measure of symptom burden. *Mplus* was used to fit 2- and 3-correlated factor models using unweighted least squares estimation. Symptoms were a priori delineated under the factor labels affective, cognitive, and sickness behavior (3-factor model) and sickness behavior and negative affectivity (2-factor model).

**Results:** Fit statistics for the 3-factor model were good:  $\chi^2(186) = 273.624$ ,  $p < .001$ ; RMSEA = .053; CFI = .949. Standardised factor loadings were generally high. The lowest standardised factor loadings were observed for agitation (.39), libido (.47), and pessimism (.54). Support for a sickness behavior factor was also observed in the 2-factor model ( $\chi^2(188) = 278.129$ ,  $p < .001$ ; RMSEA = .054; CFI = .947).

**Conclusion:** Both factor models provide initial psychometric support for the unique construct of sickness behavior in a sample of patients with advanced cancer. Results also suggest that the demarcation of other factors is less salient. Symptom clusters are recognised as a research priority that may elucidate neurobiological underpinnings and thereby improve treatment outcomes. Factor correlations with other measures of distress are presented and clinical implications are discussed.

## Non-cancer

Abstract number: P2-433  
Abstract type: Poster

### **Dignity Therapy: A Supportive Psychological Intervention for People with Motor Neurone Disease and their Family Carers**

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**Background:** There are calls to explore psychological interventions to reduce distress in Motor Neurone Disease (MND) patients and their family carers (FCs). Dignity Therapy (DT) is a short term psychotherapy intervention shown to alleviate distress for people with life limiting illnesses.

**Objectives:** To assess the acceptability, feasibility and effectiveness of DT to reduce distress in people with MND and their FCs.

**Methods:** Clients of the MND association in Western Australia were invited to participate in 2011–13. The study used a repeated measures design pre and post-intervention. Acceptability and feasibility were assessed using participants' ratings of the helpfulness of the intervention across several domains and time and resources required. Effectiveness measures for patients included: dignity-related distress, hopefulness and spiritual wellbeing; and those for FCs included burden, hopefulness, anxiety and depression.

**Results:** 27 patients and 18 FCs completed the intervention. DT was well accepted, including by patients who required assisted communication devices. There were no significant differences in all outcome measures for both groups. However, the high satisfaction and endorsement of DT suggests it has influenced various important aspects of end of life experience such as helping them attend to unfinished business and made them feel they were still themselves. FCs overwhelmingly agreed the DT document is and will continue to be a source of comfort, and they would recommend DT to others in the same situation.

**Conclusions:** This is the first DT study to focus on MND and home-based caregiving. The therapy needs to be offered earlier. Results established the importance of narrative and generativity for patients with MND and may open the door for other neurodegenerative conditions. (Funded by an Australian Research Council Linkage Grant and the MND Association of Western Australia).

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Abstract type: Poster

### **Symptoms and Palliative Care Needs of Patients with Fibrotic Interstitial Lung Disease: A Systematic Literature Review**

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**Background:** Interstitial lung disease includes a diverse number of disorders in which pulmonary fibrosis are the final common pathways of lung damage. Idiopathic pulmonary fibrosis is the most common subset of Idiopathic Interstitial Pneumonias. It is a specific form of chronic, progressive fibrosing interstitial pneumonia of unknown cause with limited and often unsuccessful treatment options. Research has shown this disease negatively affects the quality of life of patients and caregivers, and only a small number of patients with PIF-ILD have benefited from palliative care services. Little is known about the needs of this population.

**Aims:** To determine from existing studies the prevalence of symptoms among patients with progressive idiopathic fibrotic interstitial lung disease. To compare symptom profile with other chronic, progressive conditions.

**Methods:** Comprehensive searches of MEDLINE, Cochrane clinical trials database, EMBASE, Science Citation Index Expanded, pre-Medline, CINAHL and PSYCINFO for clinical studies where the target population were adults with progressive idiopathic Fibrotic Interstitial Lung Disease and for whom the incidence and prevalence of symptoms had been calculated. Inclusion criteria: prospective and retrospective studies with adult participants with advanced disease, and trials conducted between 1966 and 2013.

**Results:** A total of 4173 titles were screened for eligibility criteria. In the end 21 studies were included for analysis. Information on the prevalence of respiratory, digestive, sleep disorders, mood disorders, weight loss, urinary symptoms and pain was found. The highest prevalence was that of dyspnea (54–98%) and cough (59–100%) followed by heartburn (25.65%) and depression (10–49%). The heterogeneity of studies limit their comparability, but patients with PIF-ILD and other chronic conditions have similar complaints regarding symptoms. Further research is needed in order to better characterise these findings.

**Abstract number:** P2-435

**Abstract type:** Poster

## Dialysis or Conservative Management in Chronic Kidney Disease (Stage 5)? Evaluation of Patients in a Tertiary Hospital who Started Dialysis in 2012

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**Background:** Studies suggest that in elderly patients with Stage 5, Chronic Kidney Disease (CKD-5) the survival benefit with dialysis can be lost if there is high comorbidity and low Performance Status, and thus Conservative Management (CM) can be a valid option.  
**Aims:** To describe hospitalised patients who started dialysis in a tertiary hospital in 2012: to determine mortality predictors; and to identify patients who could have benefitted from CM.  
**Methods:** We retrospectively examined data from hospitalised CKD-5 patients, who were followed over a 23-month period. Patient data included their Karnofsky Performance Status (KPS); Mental Status (MS); Charlson (CCI); and Elixhauser Comorbidity Index (ECI).  
**Results:** Of our study sample (N=185) 57% were male, 50% were diabetic, 45% were 75 years or older (75+), 51% were admitted to Internal Medicine wards and 35% to a Renal ward. Mean follow-up was 12±6 months; 35% died, 47% during their first hospitalisation. Mortality was associated with age 75+ (p<.001); KPS< 50 (p<.001); confusion and dementia (CDMS) (p=.001); ECI>5 (p=.015); CCI>8 (p=.05), heart failure (HF) (p=.002); coronary artery disease (p=.027); arrhythmia (p=.01); and CKDEPI (p<.001). Mortality predictors in a Cox regression model were: 75+ (HR 3.2; p=0.003); HF (HR 1.9; p=0.03); CCI>8 (HR 3.6; p=0.003); CDMS (HR 2.3; p=0.003); and CKDEPI (HR 1.08; p< 0.001). The 75+ patients (n=11) who were referred early to Nephrology with HF and KPS< 50, and met standard CM criteria benefitted less with dialysis: 6 died and 1 recovered renal function.  
**Conclusions / Discussion:** CI and KPS status were useful in predicting mortality. Dialysis use and mortality could possibly be reduced by applying CM criteria. A prospective study in an outpatient renal clinic setting could identify robust CM criteria in frail elderly patients with high comorbidity.

**Abstract number:** P2-436

**Abstract type:** Poster

## Variation in Quality of Palliative Care Provided to Patients with Cancer, Chronic Organ Failure, Old Age or Dementia: The Views from Bereaved Relatives

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**Background:** There is a recognised need for palliative care for patients with non-malignant diseases, like chronic heart failure or dementia. However, the often unpredictable illness trajectories of people with conditions other than cancer may hamper provision of high-quality palliative care.  
**Aim:** The aim is to compare the quality of care in the last week of life of patients with cancer, organ failure and frailty, as experienced by bereaved relatives.  
**Methods:** An existing dataset of 458 bereaved relatives was analysed to determine the differences in the quality of care for three groups of patients; cancer, organ failure and frailty. Data had been collected with the validated questionnaire Consumer Quality Index Palliative Care for bereaved relatives. Multilevel analysis, logistic regression and linear regression were used to calculate differences between groups.  
**Results:** Differences existed regarding the perceived quality of care as received by the patient in the last week of life: bereaved relatives of patients with organ failure (n=61) and with frailty (n=182) both reported more negative experiences regarding expertise of the healthcare professionals involved, respectively OR 9.8;95%CI 1.8–52.9 and OR 4.5;95%CI 1.0–19.1. Furthermore, patients with frailty had less frequent access to a counsellor for spiritual problems compared patients with cancer (n=215), OR 5.4;95%CI 1.4–20.8, as experienced by their bereaved relatives. The bereaved relatives' quality rating of the care in the last week of the patient's life was significantly lower in the frailty group compared to the cancer group (p=0.01). No significant differences were found between the three groups regarding psychosocial/spiritual care for the patient.  
**Conclusion:** The quality of care as perceived by bereaved relatives differs between patients with cancer, organ failure and frailty. Overall, bereaved relatives of cancer patients have more positive experiences regarding the care for the patient in the last week of life.

**Abstract number:** P2-437

**Abstract type:** Poster

## PROLONG: Identification of Patients with COPD with a Poor Prognosis and Implementation of Proactive Palliative Care

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**Background:** Proactive palliative care is not yet common practice for patients with COPD. Important barriers are the identification of patients with poor prognosis and the organisation of proactive palliative care dedicated to the COPD patient. Recently a set of indicators has been developed to identify those patients with COPD hospitalised for an acute exacerbation who are at risk for post-discharge mortality. Only after identification of these patients with poor prognosis a multi disciplinary approach to proactive palliative care with support of a specialised palliative care team can be initiated.  
**Aims:** The objectives of the PROLONG study are:  
 1) to assess the discriminating power of the proposed set of indicators (indicator study) and  
 2) to assess the effects of proactive palliative care for qualifying patients with COPD on the wellbeing of these patients and their informal caregivers (intervention study).  
**Methods:** The PROLONG study is a prospective cluster controlled trial in which 6 hospitals participate. Three hospitals are selected for the intervention condition based on the

presence of a specialised palliative care team. The study population consists of patients with COPD and their main informal caregivers. Patients are included during hospitalisation for an acute exacerbation. All patients in the study receive standard care (usual care). Besides, patients in the intervention condition who meet two or more criteria of the set of indicators receive additionally regular consultations with a specialised palliative care team.  
**Results:** The primary outcome measures are time to death for any cause (indicator study) and change in quality of life three months after inclusion (intervention study). Preliminary findings are presented during the EAPC 2015.  
**Discussion:** The PROLONG study may lead to better understanding of the conditions to start and the effectiveness of proactive palliative care for patients with COPD.  
**Source of funding:** ZonMw, the Netherlands.

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**Abstract type:** Poster

## Quality in End of Life for Dying Stroke Patients

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**Background and purpose:** Stroke causes suffering in patients, but there is limited information on the quality of palliative care for patients dying from stroke. To date most palliative research has centered on patients' suffering from cancer. The aim of this study was to examine the quality of palliative care during the last week in life for patients dying from stroke in terms of symptoms, and communication and compare the results with those who died from cancer.  
**Method:** A retrospective comparative registry study was performed using data from a Swedish national quality register for end-of-life care. Data from 1626 patients deceased from stroke were compared with data from 1626 matched patients dead from cancer. Binary logistic regression analyses and odds ratio were calculated.  
**Results:** All six assessed symptoms were reported by the health care staff as being present during the last week of life in the stroke group with 63% having death rattles, 52% pain, 26% anxiety, 18% dyspnea, 11% confusion and 10% nausea. Compared to the cancer group, it was significantly more often unknown to the reporting health care staff whether the patients in the stroke group had presence of the studied symptoms and if the place of death corresponded with latest expressed wish of the patient. In addition, the stroke patients and their families had significantly lower odds to achieve informative communication about transition to end-of-life care and the family members to be offered bereavement follow-up.  
**Conclusion:** This study indicates inequalities in the quality of palliative care depending on diagnosis, and unmet needs during the last week of life of patients dying from stroke. The findings have implications for clinical practice and the need of health care staff to pay more attention to the quality of the palliative care situation of the dying stroke patient.

**Abstract number:** P2-439

**Abstract type:** Poster

## Are Patient Self-reports of Anxiety and Depression Reliable Indicators of Clinical Conditions in Advanced COPD?

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**Background:** Anxiety and depression are common in Chronic Obstructive Pulmonary Disease (COPD) and increase with its severity. Presence of anxiety/depression in COPD is associated with a number of poorer health outcomes. If patients could self-report anxiety/depression, clinical management could be instigated to potentially ameliorate effects.  
**Aim:** To identify whether patients with advanced COPD can self-report anxiety and depression.  
**Methods:** A population-based sample of 216 patients with advanced COPD answered self-report questions on how much they were bothered by anxiety/depression and completed the Hospital Anxiety and Depression Scale (HADS) to screen for anxiety/depression. Analyses first explored the association between self-reported anxiety/depression ('Not at all', 'A little', 'Quite a bit' or 'Very much') and a four-level categorisation of HADS scores: normal (0–7), mild (8–10), moderate (11–14) and severe (15–21). Secondly, we used binary categorisation of both self-report and HADS to calculate sensitivity and specificity: the HADS cut-off of 11 (for probable clinical disorder or 'caseness') and any self-report ('A little' to 'Very much') to define anxiety/depression.  
**Results:** We found a positive association between the degree of self-reported anxiety/depression and HADS score (p< 0.001 for both anxiety and depression). We found sensitivities of 85.2% and 77.8% and specificities of 56.2% and 57.9% for anxiety and depression, respectively. The majority of patients correctly identified their status (64.5% for anxiety and 60.4% for depression).  
**Conclusion:** Patient self-report of anxiety/depression is positively associated with HADS scores. Routinely asking patients with advanced COPD if they are bothered by anxiety or depression may be a useful screening question to highlight those with clinical conditions. Patients with advanced COPD who self-report anxiety/depression may be clinical cases who could benefit from treatment.  
**Funder:** NIHR & Marie Curie



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Abstract type: Poster

### The Role of a Palliative-Focused Outpatient Intervention for Patients with End-stage Lung Disease Awaiting Transplant

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**Background:** Patients with end-stage lung disease (ESLD) awaiting lung transplant suffer from a complex array of burdensome symptoms. There is a paucity of research exploring the impact of an outpatient palliative care (OPC) service for this population.

**Aims:** Our novel study was designed to explore the impact of an OPC intervention on symptoms for patients with ESLD awaiting transplant, as well as to provide further support for the role of PC in the non-malignant setting.

**Methods:** 115 patients awaiting lung transplant were referred to the OPC team from December 1<sup>st</sup>, 2011 to March 1<sup>st</sup>, 2014. Patient demographics, diagnoses, reason(s) for referral to the PC team, palliative performance score (PPS) at time of consultation, PC interventions performed, and Edmonton Symptom Assessment System (ESAS) scores were evaluated. Of the initial 115 referrals, 65 patients completed ESAS scores for both the initial consult and follow-up visit. Using paired t-tests, changes in symptom scores were assessed.

**Results:** 50.4% of patients were male. The most common diagnosis was interstitial lung disease (65.2%), followed by COPD (12.2%) and other (22.6%). Over 93% of patients had a PPS in the transition zone (60–40) at time of consult. The initiation of opioids for relief of breathlessness was the most common intervention performed. Changes in symptom scores after referral were: pain -0.5 (P< 0.12), tiredness -0.5 (P< 0.16), nausea -0.2 (P< 0.47), depression +0.3 (P< 0.44), anxiety -0.3 (P< 0.4), drowsiness -0.3 (P< 0.45), appetite +0.3 (P< 0.4), wellbeing -0.1 (P< 0.74), shortness of breath +0.2 (P< 0.56), constipation 0.0 (P=0.70), sleep -1.7 (P< 0.0001), and cough -0.7 (0.03).

**Conclusion:** The initial consult by the OPC team achieved significant improvements in sleep. Other symptoms captured in the ESAS neither improved nor worsened significantly. Further investigation into the role of palliative care in the ESLD population awaiting transplant is warranted.

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### Perceptions of Healthcare Professionals Regarding the Transition to a Palliative Approach to Care in Advanced Heart Failure

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**Background:** National and international consensus guidelines recommend a palliative care approach in heart failure but this has not been widely implemented and clinicians find it hard to identify when a transition to palliative care should occur.

**Aims:** To explore health care professionals' perceptions of decision making and communication regarding the transition to a palliative approach to care in heart failure.

**Methods:** (design, data collection, analysis) Qualitative focus groups were conducted with a broad range of health care professionals with experience of caring for patients with heart failure and palliative care needs from cardiology, primary care and specialist palliative care. A topic guide was used. Groups were recorded and verbatim transcribed. Data were analysed using a thematic framework according to specialty. Interactions and group dynamics were noted and used to help understand the themes emerging from the data.

**Results:** Seven focus groups with clinicians were conducted and major themes and quotes are presented in the table.

	Cardiology	Primary care	Specialist palliative care
Recognition of transition to palliative care	'but I think everyone knows the exact kind of patients'	'Whereas for heart failure you don't have such a clear message from the specialist'	'The heart failure nurses being outstanding and pivotal in that connection between hospital, hospice and community, they just bridged it so wonderfully'
Comparison with cancer	'once you're diagnosed with cancer people expect you to die... whereas many heart failure patients do not expect to die very soon'	'Its very streamlined, oncology, palliative, Macmillan'	'The heart failure, neurology patients, respiratory patients, get eight visits' (to day hospice) cf cancer patients
Importance of integrated palliative care	'...and we look at the weight charts, at the blood pressures, we mess about with the drugs and we don't actually deal with what the patients have a problem with'	Importance of heart failure nurses 'blessed' Positive effects for patients 'tangible feeling of relief'	'Two way process, learning from each other'

[Major themes with illustrative quotes]

**Conclusion/ discussion:** The data support an integrated approach to a palliative care in heart failure and the pivotal role of the heart failure nurse specialist or other key worker to coordinate care.

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Abstract type: Poster

### Bridging Disciplinary and Professional Gaps: Psychologist as Key Worker within MND

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**Background:** Our centre was established as national tertiary unit in 2006, has cared for some 800 MND patients and families: many travel for several hours. As a high resolution centre, coordination must be excellent.

**Aims:** To establish the role of the team psychologist in a metropolitan MND unit as the professional to streamline highly complex expert care, offering care, support and advice underpinned by research. To offer a person centered model of care balancing life expectancy and difficulty in treatment adherence.

**Methods:** Retrospective descriptive study from 7 years data from comprehensive data base, register and management instruments: reports, appointment records, annual reports, guidelines and protocols. Showcase the Psychologist Key Worker (PKW) role as guide from diagnosis through multidisciplinary and experimental treatments, surgery, ventilation, Palliative Care and Care management in their geographical area through to death and bereavement care.

**Results:** 751 patients included: 57,5% were men and 42,5% women. 45% were from this region; 54% from other regions and 1% from abroad.

The two psychologists offered a total 3.285 interventions as key worker while offering their input as team psychologists. Key worker interventions have multiplied by a factor of 14. Currently 349 patients remain in our books (54%) have died, of which 29,5% died in our unit, 16% in hospital, 12,5% in their own home; 0,5% in other institutions and 0,5% in the ambulance. The analysis of the trends show a strong component of Alleviated anticipated suffering and Reduced feelings of lack of control and unsafety, reported by patients and families. Reduced number of unnecessary admissions and re-admissions.

**Conclusion:** PKW underpins the MND Care Process, negotiating the health system offering high quality response to global care, structuring it within a short time. The model offers good planning and coordination of care promoting quality of care and reducing expensive fragmented care.

Abstract number: P2-443  
Abstract type: Poster

### Financial Implications for People Dying with Advanced Dementia in Care Homes in England

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**Background:** The Care Act 2014 framework enables a local authority to decide how much to charge, if at all, when meeting a person's care and support needs. The overarching principle is that people should only be required to pay what they can afford.

**Aims:** To explore financial dimensions of well-being among people dying with advanced dementia in care homes in England.

**Methods:** Using data of weekly charges levied by 10 care homes across Greater London and the guidelines for financial assessment, we synthesise the findings to provide a view of residents' financial well-being.

**Results:** Across 10 care homes, the mean charge for weekly stay is £734 (std dev £163). In our sample of 70 residents (median age 85, 79% female, 79% White British/Irish, FAST score 7a–7c 68%, 7d–7f 32%), almost ¾ are fully funded by the local authority for their stay at a care home, indicating that savings and assets they hold are under the threshold of £23,250 as set out by the Care Act financial assessment guidelines. A quarter of residents are partially funded by the local authority with a weekly mean personal contribution of £316 (std dev £201). This corresponds to their average personal net worth of around £47,000, which is still below that of a typical UK pensioner. Only 1 patient paid full charges out-of-pocket, indicating above national average personal wealth.

**Conclusion:** While average pensioner incomes have risen significantly in real terms in the past decade, the personal wealth of the majority of patients dying with advanced dementia in care homes across Greater London are in the lowest 10% of pensioner population. On average, they are unlikely to be home-owners, have occupational pension, sizeable net savings or investments. With rates of dementia set to increase, government policy needs to address challenges for future funding of care.

Source of funding: Marie Curie Cancer Care (grant ref. MCCC-FPR-11-U) administered in partnership with Cancer Research UK



**Abstract number:** P2-444

**Abstract type:** Poster

## Patient-reported Outcomes in Primary and Acute Settings in South Africa: The IMPACT Study

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**Background:** The burden of progressive illness (particularly NCDs) falls greatest in low and middle income countries, where to date research has focused on HIV and cancer patients. This novel study aimed to measure longitudinal patient-reported outcomes and health service use among COPD/heart failure patients attending primary care.

**Methods:** Consecutive patients with stage III/IV CHF or V/VI COPD breathlessness were invited to participate. Each gave self-report data using the POS (Palliative Outcome Scale), with worst score=0, best=5. Each completed 4 monthly time points. The analysis determined:

- 1) Worse items at baseline;
- 2) score changes over time using non-parametric matched scored analysis performed between first/last timepoints;
- 3) Descriptive health service; 4) Determined associations between POS total score and service use.

**Results:** N=104 recruited, 78% CHF, 26% both CHF & COPD. Mean KPS=61.2 (SD=7.6).

1) Worst problems: sharing feelings, life worthwhile, being at peace, advice to plan (all median=2).

2) The following items showed score worsening over time: sharing feelings (p=0.020), life worthwhile (p=0.014), at peace (p<0.001); help and advice to plan (p<0.001). Around a quarter of the sample reported worsening pain, symptom and worry scores.

3) Over 4 months, there were n=662 primary care contacts, n=525 outpatients, n=567 other HCW, and n=602 hospital admissions.

4) Baseline total POS score associated with more outpatient visits (p=0.021) and a trend for more admissions (p=0.078).

**Conclusion:** There is a high multidimensional burden of palliative-care related problems among people with chronic disease in primary care, and a high level of service use. These data have been used for a quality improvement plan, including data-driven training, clinical mentorship and repeated outcome measurement.

**Abstract number:** P2-445

**Abstract type:** Poster

## Non-malignant Referrals to an Irish Hospital Specialist Palliative Medicine Service – The Rising Tide

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**Aim:** Analysis of the trend of non-cancer referrals to the Specialist Palliative Medicine Service (SPMS) at St. Vincent's University Hospital between 2009 and 2012.

**Methods:** Approval was granted from the Clinical Audit Department. The electronic Palliative Care Database was used to identify all patients with a non-cancer diagnosis referred to the SPMS during 2009 and 2012. Data was collected from patients' medical records and both the hospital and the SPMS's Patient Administration System (PAS) and collated on Excel. Data was analysed using SPSS.

**Results:** The number of individual patients without cancer referred to the SPMS rose from 92 in 2009 (22% of referrals) to 221 in 2012 (35.6% of referrals). End-of-life care was the most common reason for referral in 2009 (55.4%, n=51) while symptom control was the most common reason for referral in 2012 (78.7%, n=174) (p=0.000). 2012 saw a marked increase in the referral of patients with neurological conditions such as motor neurone disease, stroke and dementia, as well as respiratory conditions, particularly cystic fibrosis. New 'non-malignant' conditions referred in 2012 included cerebral palsy (1.4%, n=3) and Parkinson's disease (2.3%, n=5). While there was no record of fentanyl use by continuous subcutaneous infusion in 2009, it was the opioid of choice in 5% of the 2012 sample (p=0.03).

**Conclusions:** There is an increasing recognition that palliative care services should be accessed on the basis of need rather than diagnosis. Our service is adapting to accommodate a marked increase in the number of non-malignant referrals, as well as a broadening of conditions referred and is working to promote a shared-care model of timely referral, focusing on enhancing quality of life and not primarily focused on end-of-life care.

**Keywords:** Non-malignant, palliative medicine, referral-patterns, symptoms, end-of-life

**Abstract number:** P2-446

**Abstract type:** Poster

## Managing Parkinson'S Disease in the Last Days of Life – A Guide for Clinicians

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**Background:** Current guidance for the management of Parkinson's disease patients in the last days of life is limited, particularly with regard to pharmacological treatments when patients are unable to swallow reliably.

**Aims:** To produce specific guidance for symptom control and use of anti-parkinsonian medications in patients with Parkinson's disease in the last days of life.

**Approach:** A literature review was undertaken to examine evidence for the use of anti-parkinsonian medications in the last days of life. In conjunction with this, existing regional and national UK clinical guidance was evaluated. Summary of product characteristics

information was examined and local professional consensus sought. A multi-disciplinary working group including consultant physicians, specialist pharmacists and clinical nurse specialists subsequently worked to produce detailed written clinical guidance.

**Results:** A detailed document has been produced with guidance on the use of all common anti-parkinsonian medications in the last days of life. This includes information on dose and formulation of medications given orally or via enteral feeding tubes as well as transdermal and subcutaneous drugs. Advice for symptom control issues specific to this patient group is also included. Flow charts have been produced to simplify the initiation of the rotigotine transdermal patch depending on previously used anti-parkinsonian drug doses. Contact links to a network of local specialists in Parkinson's disease and palliative care are included.

**Conclusion:** This comprehensive and practically useful new clinical guidance provides an excellent resource for health professionals treating a patient group with often complex needs. Pilot implementation is taking place in a University teaching hospital with additional plans for adoption across two hospice sites, with the intention that this work will evolve to become wider regional guidance.

**Abstract number:** P2-447

**Abstract type:** Poster

## Interventions Involving Patient-centred Care in Chronic Heart Failure – A Systematic Review

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**Background:** Chronic heart failure (CHF) is a progressive life-limiting condition with a considerable disease burden and poor quality of life complicated by unaddressed communication needs. Prognosis is difficult to predict and treatment decisions are complex. Patient-centred care (PCC) recognises the external and internal factors influencing the patient as person and enables patients to play an informed, active role in decision-making about their goals of care, but the best way to achieve this in clinical settings and PCC intervention outcomes are unclear.

**Aims:** To identify PCC interventions and outcomes for patients with CHF.

**Methods:** Searches were undertaken in Medline, Embase, PsycINFO, Cinahl, Assia, the Cochrane Library, clinicaltrials.gov, journals and in citations for studies that examined PCC interventions in patients with CHF staged II to IV using the New York Heart Association (NYHA) classification. Study quality was assessed using the Down and Black appraisal tools for randomised and non-randomised studies and a narrative synthesis was undertaken.

**Results:** Of 12,280 studies, 10 eligible studies were identified. PCC interventions focused on collaborative goal setting between staff and patients, although considerable variation in interventions was found. Core elements included patient motivation, patient-identified goals and trust between staff and patients. Four interventions emphasised the need for improved communication to identify barriers to patients taking a more active role in their care. An overall trend towards improved health-related quality of life, reduced symptom burden, reduced readmission rates and enhanced patient engagement was evident.

**Conclusion:** PCC interventions with patient motivation, patient-identified goals and trust between staff and patients lead to improved outcomes and processes for patients with CHF. More studies are needed to further determine the core ingredients of effective PCC interventions.

**Abstract number:** P2-448

**Abstract type:** Poster

## Palliative Care for Patients with Non-cancer or Particular Conditions in the Netherlands

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**Aim:** The aim of this study was to gain insight into what topics are considered as priorities for improving the quality of palliative care for patients with non-oncological disease such as stroke, COPD, dementia or heart failure or patients with a psychiatric disorder or mental disability by professionals in the Netherlands.

**Method:** A digital survey was developed and widely disseminated among professionals involved in one of the six target groups mentioned above. The questions concerned the extent to which certain challenges of improvement were recognised and which remedial actions deserved priority.

For each target group a top three of desired developments was drawn. Results were compared between different sectors of healthcare and professional groups.

**Results:** The survey yielded 1,184 usable responses. Of the respondents, 40% work in the sector of primary care, 25% in hospital, 20% in nursing homes and 4% in a hospice. One third is employed as a consultant in palliative care or in a hospice, but their response did not differ significantly from the rest. Three quarters of the respondents consider improving palliative care for non-oncological groups as needed.

By each target group specific priorities are identified.

Most frequently mentioned improvements were:

- To actively disseminate existing guidelines, methodologies, and services,
- To foster regional (transmural) cooperation,
- To educate health care providers in hospices and consultants in palliative care with regard to non-oncological disease.

**Conclusion:** There is support and potential for enhancing palliative care for patients with non-oncological or particular conditions.

In our study the six target groups differ in stage of development with respect to palliative care.

Therefore, each target group requires a specific approach to improve palliative care.

**Abstract number:** P2-449  
**Abstract type:** Poster

## An Examination of Prognostic Factors Including the Systemic Inflammatory Response in Patients with Heart Failure

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**Background:** Due to the varied trajectories that exist in heart failure as patients conditions decline, it is important that optimal risk stratification of patients occurs. Improved prognostic methods are to achieve this.

**Aim:** The study compares validated prognostic factors (e.g. age, male gender, New York Heart Association classification, ejection fraction, N-terminal pro-brain natriuretic peptide (NT-proBNP), atrial fibrillation, and haematological markers) with an inflammation-based score combining CRP and Albumin (modified Glasgow Prognostic Score – mGPS), in patients with heart failure (HF).

**Methods:** A prospective open label observational study was conducted in a tertiary cardiac centre based in the United Kingdom between July 2005 and July 2007. Patients were recruited consecutively and met the following key criteria: over 18 years, LV systolic dysfunction or preserved systolic function but clinical diagnosis of heart failure. Key prognostic markers were examined and the relationship between these and survival was examined using Kaplan-Meier and Cox regression methods.

**Results:** Data were available on 127 patients. The median survival (IQR) was 48.7 months (16.2–92.9). The median EF (IQR) was 38.0 (26.0–51.0) demonstrating that the majority of patients had left ventricular systolic dysfunction. Forty-eight percent of patients had a NYHA functional classification of  $\geq 3$ . On univariate survival analysis, age ( $p=0.002$ ), NT-proBNP ( $p=0.045$ ), and mGPS ( $p<0.001$ ) were significantly associated with survival. On multivariate survival analysis, the most highly predictive factors were age (HR 1.64,  $p=0.001$ ) and mGPS (HR 1.62,  $p<0.001$ ).

**Conclusion:** An inflammation-based score, the mGPS, predicts survival in cardiac failure, is readily available to all heart failure teams and could be useful in risk stratifying and guiding therapy strategies for these patients.

**Abstract number:** P2-450  
**Abstract type:** Poster

## Health-related Concerns of Young Adults with Life Threatening Non Cancer Conditions, a Need for Palliative Care?

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**Background:** There are increasing numbers of younger people living with a chronic condition. Chronic disease has been highlighted as a priority (NHS Outcomes Framework), and quality of life in long-term conditions is one of five key areas in the NHS Mandate. Disease complications mean frequent hospital visits and patients often die in hospital, however palliative care involvement is limited.

**Aims:** To explore awareness of, attitudes to, and preferences for palliative care services including advance care planning among young adults with chronic disease.

**Method:** In-depth qualitative interviews with young adults from three disease groups; cystic fibrosis, sickle cell disease, and chronic kidney disease. Participants were purposively selected by sex, age and disease stage. Interviews were recorded, transcribed verbatim, and coded using a constant comparative approach until data saturation.

**Results:** 17 interviews (10 men), median age 34 years (range 24–50 years), revealed consistent participant preference for palliative care involvement to address physical symptoms, psychological distress and the challenge of advance care planning. Themes included:

- i) the importance of symptom control, expressed alongside the limitations of current symptom management,
- ii) major social and psychological support needs, often unaddressed, with reluctance to further burden family and friends, and
- iii) limitations in current scope to plan ahead for future care, with an overt and expressed need for advance planning.

**Conclusion:** This work highlights the need to address the health-related concerns of young adults with life threatening non cancer conditions. Emphasis needs to focus on planning for the future if we are to improve the quality of life for these young adults, and deliver care that meets patient choice and preference. One key challenge is to understand how advance care planning can be applied successfully in this cohort of young adults.

**Abstract number:** P2-451  
**Abstract type:** Poster

## Establishing and Addressing the Palliative Care Needs of People with Advancing Neurological Disease (AND)

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**Background:** Within Ireland, there is a lack of consensus and direction with regard to the palliative care needs of people with AND. Staff members and volunteers of organisations that are members of a neurological umbrella organisation informed this study. The population total was fourteen.

**Aims:**

This study aims to:

- Investigate neurological organisations' understanding of palliative care.
- Investigate how organisations identify and respond to the palliative care needs of their members.
- Provide a greater understanding of the palliative care needs of people with AND.
- Give direction to the supports, resources and developments required to respond to needs identified.

**Methods:** A literature review and a series of qualitative interviews were carried out. Interviews were recorded and analysed using NVivo to identify themes.

**Results:**

1. The literature review and interviews identified that ambiguity exists around the terminology of palliative care. Palliative care is primarily associated with specialist services. The following issues arise for organisations:

- Difficulty accessing palliative services
  - Uncertainty when palliative care begins
  - Planning Ahead
  - The requirement for training
- The following themes were identified by participants as a means of enhancing palliative for this group:
- Greater understanding of symptoms and unpredictable nature of illnesses.
  - Emphasis on interventions that support quality of life and planning ahead.
  - Availability of palliative care approach earlier.
  - Enhanced multidisciplinary and psychosocial care
  - Increased equitable access to specialist palliative care
  - More training for staff

**Conclusion:** Collaboration among all stakeholders is required to ensure the palliative care needs of those with AND are adequately addressed.

**Abstract number:** P2-452  
**Abstract type:** Poster

## The Palliative Care Needs of People with Young Onset Dementia: A Literature Review

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**Aim:** This piece of work was carried out to explore the palliative care needs of people with young onset dementia and inform the development of guidance documents that are being prepared.

**Design:** A review of the literature was carried out by searching key terms on the databases CINAHL and PubMed, searching academic journals and non-academic grey literature websites. Articles retrieved were assessed for relevance and information was synthesised by identifying prominent themes. The themes to emerge are: 'Diagnosis', 'Impact on family', 'Services' and 'Quality of life'.

**Results:** The literature indicates the following:

There is a research and practice gap regarding the palliative care needs of this group. Receiving a timely diagnosis and engaging in advanced care planning are of crucial importance.

Family members/ carers are impacted financially, socially and emotionally by taking on a caring role and experience ambiguous loss throughout the caring role.

Services accessed are largely inefficient and inadequate at meeting peoples' needs.

Living with young onset dementia impacts on quality of life but caution must be taken in reaching negative assumptions.

**Conclusion:** People are living and dying with young onset dementia and numbers look set to rise in the coming years. This review identified very few pieces of research about this topic thus signifying the need for further exploration via the use of a case study. This is important so as to inform society, policy makers and service providers about the needs of people with young onset dementia.

**Abstract number:** P2-453

**Abstract type:** Poster

## Deactivation of an Implantable Cardioverter Defibrillator (ICD) – How Do Professionals Decide?

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**Background:** The therapeutic benefit of an Implantable Cardioverter Defibrillator (ICD) during the last stage of any illness remains uncertain. International guidelines recommend professionals discuss deactivation with patients, but literature suggests this rarely occurs. **Aim:** To identify factors that impact on professional judgement regarding deactivation of an ICD at end-of-life.

**Methods:** This involved two phases: 1. Systematic narrative review of 19 empirical studies on patients' perceptions of deactivation. Phase 2: Semi-structured interviews with patients (n=9), carers (n=9) and professional focus groups (n=7). Data were combined to identify and conceptualise factors affecting decision making

**Results:** Nine factors (italics) were identified. Majority of patients included within the published studies and interviews were male (*gender*), median age 64 years (*age*) and lived with a family member (*social support*). Qualitative data showed that many patients' were reluctant to engage in a *discussion* through-out their illness until '*at death's door*' (49 year female). Frequent *shocks* prompted patients to consider deactivation and was viewed by professionals as indicative of a discussion. Professionals mentioned *number of hospital admissions* as a sign of clinical deterioration Ethical and legal considerations dominated in clarifying *treatment intent*. Patients felt ill-equipped i.e. '*Noone has the right to make the decision for you who is not medically trained*' (60 year male). Despite being elderly with deteriorating heart failure symptoms (*heart failure severity*) patients anticipated surviving more than 10 years. Many professionals felt that unless patients had a cancer diagnosis (*comorbidity*) they were less likely to engage in a discussion.

**Conclusion:** It is postulated that the nine implicit factors identified affect professional decision-making about ICD deactivation at the end-of- life. These have been developed into a web-linked professional factorial survey.

**Abstract number:** P2-454

**Abstract type:** Poster

## Palliative Care for People with Chronic Obstructive Pulmonary Disease is a Neglected Area in Primary Healthcare

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**Background:** Patients with chronic obstructive pulmonary disease (COPD) are underserved in the primary sector and receive less palliative care than patients with other diseases with comparable symptoms and prognoses.

**Aims:** To examine health professionals' reflections, experiences and considerations on palliative care for people with COPD in primary healthcare.

**Methods:** In the period August–September 2014, 66 health professionals (nurses, assistants and helpers) participated in a 120-minute group interview. Ten group interviews with 3–8 participants were completed. The health professionals were invited from eleven homecare districts in Denmark and the interviews were analysed descriptively. Five mayor questions were discussed during the interviews: what is palliation and who needs palliative care; what are the challenges in working with COPD sufferers; how do you identify palliative care needs; do you initiate discussions with patients about the future; and are you able to respond to patient's palliative care needs?

**Results:** The participants expressed vague definitions of palliative care services to patients suffering from COPD; revealed urgent need for knowledge; and thought it was difficult to find the right time for serious conversations about future life concerns related to COPD. The participants considered good relations and clear agreements to be important for the patients' confidence but felt unable to help and support the patients during crisis of breathlessness and anxiety.

**Conclusion / Discussion:** Palliative care for people with COPD is a neglected area. Primary health professionals are eager to learn about COPD and how to manage palliation, relieve symptoms and communicate.

**Abstract number:** P2-455

**Abstract type:** Poster

## Bode Index as Screening Tool for Referring COPD Patients to Palliative Care

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**Aims:** To establish the utility of Bode Index to detect COPD patients needing palliative care interventions.

**Methods:** This is part of a larger study between the Respiratory Department and the Palliative Care team (PCT). Patient attending the outpatients COPD clinic were able to take part after informed consent. Two independent blind assessments were done by pneumologists and palliative care physicians. At the COPD clinic, a part from the routine Global respiratory assessment including: spirometry, 6 minutes walking test, Dyspnoea by the Modified Medical Research Council Scale and Body Mass Index to perform the BODE Index : At the PCT, a global assessment was developed including: Edmonton Assessment

system was completed, functional assessment by Palliative Performance Scale and Psychosocial situation. Statistics: Descriptive analysis by central tendency measures and frequencies and correlation and comparative analysis was performed by non parametric tests. Spearman correlation was used and Classification and Regression Tree (CART) was use to establish the best BODE index level for palliative care referral.

**Results:** 50 patients were included, 2 patients were excluded because missing data. Mean age was 71.2; male 66%. Mean number of symptoms were 5. The median of symptoms' intensity was 3. Dyspnoea was the most important symptom. PPS median was 70. BODE average was 3.1. We identified good inverse correlation between PSS and Bode Index (CC = - 3.94 p>0.01). BODE index more than 5 can identify patients needing palliative care intervention either as outpatients or at home.

**Conclusion:** BODE Index can be use by pneulogists to refer patients to palliative care teams.

**Abstract number:** P2-456

**Abstract type:** Poster

## Physical Symptoms and Comfort in People with Advanced Dementia: A Longitudinal Cohort Study

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**Background:** People with advanced dementia often have poorly managed physical symptoms and need better quality care at the end of life.

**Aims:** To describe symptoms in people with advanced dementia and inform development of a complex intervention to improve care.

**Methods:** Longitudinal cohort study of people with advanced dementia (Functional Assessment Staging Scale ≥6E) with assessments at study entry and every month for 9 months or until death. Tools included: Bedford Alzheimer Nursing Scale (BANS), Charlson Co-morbidity and Waterlow Scores, Pain Assessment in Advanced Dementia Scale (PAINAD), Cohen–Mansfield Agitation Inventory (CMAI), Symptom Management at the End of Life in Dementia (SM-EOLD), Comfort Assessment in Dying with Dementia Scale (CAD-EOLD) and Quality of life in Advanced Dementia (QUALID).

**Results:** We recruited 85 participants (93% residing in a care homes, 79% female, median age 85 years, 79% white British, median assessment visits-6 per person). At first visit median BANS score was 21, 38% were high risk and 53% at very high risk of pressure sores, 42% had difficulty swallowing, 76% needed assistance with eating, 34% had weight loss and 27% were asleep for most of the day, 14% had excess respiratory secretions and 13% had breathing problems. On the PAINAD 15% had pain at rest and 68% at movement, increasing to 61% and 100% respectively at last visit. CMAI scores increased from median of 41 to 51 during the study. QUALID scores were median 23 at baseline to 30 at final visit) showing reduced QoL. Median SMEOLD score was 33 at baseline rising to 40 at last visit. 26 participants died during follow up with a median CAD-EOLD score of 37.

**Conclusion:** Our population was frail and at high risk of pressure sores. Pain was common; this, clinically significant agitation, and quality of life worsened over time. As well as defining symptom trajectory these data inform the development of a complex intervention and highlight which symptoms should be considered.

**Abstract number:** P2-457

**Abstract type:** Poster

## Re-engineering Dialysis: The Role of Palliative Medicine

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**Background:** End-stage renal disease(ESRD) is a life limiting illness with significant morbidity. Half are unable to participate in decision making at the end of life. Advanced care planning(ACP) is critical in this population. We sought to determine the impact of routine palliative medicine(PM) consultation on patients with ESRD.

**Aims:**

1. Determine the feasibility of embedding PM consults in the HD unit during HD runs.
2. Determine impact of PM consultation on ACP.

**Method:** Adults receiving HD at a single HD unit were considered eligible. Patients were excluded if they declined consultation. All consultations occurred during the patient's HD run over a 6-month intervention period.

Medical records were reviewed for documentation of advance directive, code status and GOC discussion before and after PM intervention.

Pre and post analysis was done using McNemar's test.

**Results:** 92 patients were eligible. 91 patients underwent PM consultation. One patient not seen was hospitalised and unavailable but was included in the analysis. Prior to PM intervention 66 patients were full code, 21 had an unknown code status and 5 were DNR. After intervention 75 patients were full code, 1 had an unknown code status and 16 were DNR. Prior to intervention, 3 patients had documented GOC discussion in their medical record. Following intervention, GOC documentation rose to 54. The number of patients with an advanced directive on file increased from 38 to 42.

**Conclusion:** PM consultations during HD were well received by patients. The prevalence of advanced directives did not increase with embedded PM consultation. The frequency of GOC documentation and clarification of code status increased significantly. Embedded PM consultation is effective in improving ACP in the ESRD population.

	Pre	Post	P-value
Code status DNR	5/92(5%)	16/92(17%)	<0.0001
Advance Directives, yes	38/92(41%)	42/92(46%)	0.2207
GOC Discussion, yes	3/92(3%)	54/92(59%)	0.0034

[Table 1]



## Palliative care for older people

Abstract number: P2-458

Abstract type: Poster

### Putting the EAPC White Paper on Dementia into Practice – Development of a Practice Guideline

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**Background:** Dementia is a progressive degenerative disorder causing severe cognitive impairment, behavioral disturbances, and loss of ability to perform activities of daily living. The median survival time from onset of dementia to death is 4.1 years for men and 4.6 years for women. Severe dementia corresponds to score < 9 on MMSE. Aspiration, infections, and eating problems are the most common causes of death. Awareness of palliative care needs in these patients lead to the EAPC white paper on Dementia.

**Aim:** To review care provided to people with advanced dementia according to the eleven domains of the EAPC white paper.

**Methods:** Purposive sampling employed for retrospective chart review of patients with end stage dementia (2010–2012). 11 domains identified by the EAPC paper used as gold standard for comparison.

**Results:** 23 cases reviewed from 2010–2012, average age 84yr, median PPS 30(10–60), 91% patient's non verbal. 48% cared for at home, 52% in nursing home. Median duration of palliative care 17days (1–117days). 78% patients died. Each EAPC domain was assessed and data recorded. Patients presenting at end of life with multimorbidity and increased symptom burden. On review, clear evidence of targeted symptom control, holistic approach, family involvement as proxy decision makers, equitable access. Key targets for development include the inclusion of validated assessment tools to aid prognostication, improved liaison with psychiatry and gerontology, proactive care planning to address patient preference for place of care, nutrition and transfers, and increased education for staff within the unit.

**Conclusions:** Dementia is a debilitating terminal illness with features demanding a tailored approach to palliative care provision. The EAPC paper provides a framework on which to build effective and proactive practice. A clinical practice guideline incorporating validated assessment tools was developed to guide palliative care provision to patients with dementia.

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Abstract type: Poster

### Dying in Nursing Homes: A Focus Group Study Exploring Health Care Professionals' Attitudes

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**Background:** While palliative and end of life (EoL) care needs of nursing home residents are widely acknowledged, little is known about health care professionals' (HCPs) views, concerns, and specific requirements regarding EoL care in these facilities. The aim of this study was to explore factors and barriers that possibly interfere with providing palliative care.

**Methods:** In a German 300-bed nursing home, 3 focus group interviews were performed with the following pre-defined groups:

- (A) nurses/nurse aides,
- (B) nursing managers, and
- (C) physicians. Participants were recruited by a trained palliative care facilitator.

The group discussions were audiotaped, transcribed, and analysed for relevant themes.

**Results:** There were 10 participants in group (A), 9 in (B), and 3 in (C). Common themes emerging were: lack of time, training, and resources limiting appropriate EoL care, dissatisfaction with communication (both among HCPs and with families), high motivation to provide good EoL care, responsibility for residents until death, high confidence and familiarity with EoL care, usefulness of defining a 'palliative care' phase, existential questions, and lack of team support measures such as supervision. Group-specific themes were: experience of being discouraged by management (A), 'giving life' to palliative/EoL care, benefits of a mobile palliative care team (B), legal concerns regarding decision making, and limited benefit of a mobile palliative care team (C).

**Conclusions:** Despite numerous existing guidelines that regulate EoL care in long term care facilities, various issues related to structure and process have to be addressed. HCP's needs may differ among professions. Common terminology regarding palliative/EoL care and feasible criteria that trigger palliative care interventions should be adopted.

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Abstract type: Poster

### ZULIDAD – Zurich Life and Death with Advanced Dementia Study

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**Background:** Due to the ageing of the Swiss population dementia is an increasing challenge for both individuals and the health care system in general. However, key questions in the health care delivery for patients suffering from dementia, many of which live and die in nursing homes, remain unanswered.

**Aims:** As part of a Swiss national research priority program on end of life, the Zurich Life and Death with Advanced Dementia (ZULIDAD) study investigates the last phase of life of nursing home residents with advanced dementia in Switzerland.

**Methods:** The ZULIDAD study consists of three complementary parts: ZULIDAD-A, ZULIDAD-B and ZULIDAD Round Table. Based on the Resident Assessment Instrument – Minimum Data Set (RAI-MDS), ZULIDAD-A prospectively collects health status and mortality data from residents (n=20'000+) of several hundred nursing homes in Switzerland. ZULIDAD-B is an in-depth prospective study of nursing home residents with advanced dementia (n=150) who live in eight nursing homes in Zurich. Participants of ZULIDAD-B are followed for three years or until their death from two perspectives including their family members and professional caregivers who are asked to fill questionnaires about satisfaction with care, quality of care, quality of life and advanced directives. The ZULIDAD Round Table consisting of representatives of three relevant stakeholder groups (family members, professionals and researchers) serves as a supervising instrument during the entire course of ZULIDAD as well as as an instrument for disseminating the study results of ZULIDAD A and B.

**Results:** First results from the baseline assessment of the ZULIDAD-B study as well as from the Round Table ZULIDAD will be presented.

**Conclusion/ discussion:** The ZULIDAD study is the most comprehensive study on nursing home residents with advanced dementia in Switzerland. It will provide patients, families, and health care professionals with unique data on which to base their care decisions.

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Abstract type: Poster

### Bridges to Advance Directives – Readiness to Sign, among the Elderly

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**Background:** In 2005 the Israeli Knesset passed the 'Dying Patient Law', which includes the Advance Medical Directives (AD) form, by which the individual makes known his/her wishes regarding treatment, or withholding of treatment, at the terminal stages.

**Aim:** To explore factors that increase or decrease readiness to sign AD.

**Methods:** Lectures on the subject were given before 747 old people, in residential care and the community (2011–2013). 336 subjects (mean age 79.2 SD 8.9, 75.8% female) filled in validated questionnaires that included socio-demographic factors, knowledge, attitudes, choice of treatment and quality of life.

**Findings:**

1. 256 (76.2%) were ready to sign AD, including 97 (28.9%) who had already signed.
2. Factors predicting readiness to sign by regression analysis: participation in lectures (OR-3.3, p=0.01), previous discussion of subject (OR-1.49, p=0.002), arguments for signing (OR-2.42, p< 0.001) and arguments against (OR-0.245, p< 0.001).
3. 60%–81% wanted to forgo life-saving treatments and invasive therapies, while only 17%–44% wanted to forgo palliative treatments during terminal stages. The factors predicting the avoidance of fluid and nutrition drip-feed: actual signing of AD (OR-2.1, p=0.052), arguments for signing (OR-1.59, p< 0.002) and arguments against (OR-0.608, p< 0.001).
4. 51.7% decide for themselves to fill AD forms, while only 24.1% thought that health care professionals could influence them.

**Conclusions:** AD are intended to give patients informed control over treatment during terminal stages, so as to reduce unnecessary suffering. This study showed that most subjects were willing to sign AD forms and that provision of reliable information through lectures and conversations with family and professional staff, tend to increase willingness to sign. The patient should be the first to be consulted over signing AD and others, such as relatives and health professionals, should also be involved.

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### Needs of People with Severe Dementia – The Priority of Personhood

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**Background:** An increasing number of people affected by dementia is expected worldwide. There is rare empirical evidence about needs of people with severe dementia especially at the end of life.

**Aims:** The study aims to identify the needs of people with severe dementia living in residential care in Germany.

**Methods:** A qualitative study using a grounded theory approach was conducted. Participative observation of residents and group discussions with family members and health professionals were chosen for data collection.

**Results:** Observation of 30 residents, eight group discussions and three interviews with health professionals and family members were performed. Analysis showed a variety of different needs which had a unique appearance to each resident. Related to individual personality, identified needs had a specific level of significance in each resident. Residents used a variety of verbal and nonverbal means of communication such as single words, bodily tension, moving head, moaning or sounding to express their needs. Examples of identified needs were

- physical needs, eg*
  - absense of pain
  - to move and being moved
- psychosocial needs, eg*
  - minimised external stimuli
  - to interact with someone
- spiritual needs, eg*
  - to express religiousness
  - to take part in religious rituals.

**Discussion:** People with severe dementia had a variety of needs which were familiar to some needs presented in the literature for other palliative patient groups without dementia. The study stressed the demands for individual person-centered care as basis for caring strategies and fulfilling the needs of people with severe dementia. It will be important to train health professionals and increase sensibility for expression of needs and for the complexity and individuality of needs to find ways to meet them suitable to each resident.

The study is funded by the Federal Ministry of Family Affairs, Senior Citizens, Women and Youth (BMFSFJ30115N0700).



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## Predictors of Tube Feeding in End Stage Dementia, in European Long-term Care Facilities

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**Background:** Tube-feeding causes discomfort but does not prevent aspiration, prolong life, or improve nutritional status, in patients with end stage dementia.

**Aim:** Aim of this study is to investigate occurrence and predictors of tube feeding (TF) in end-stage dementia in long-term care facilities (LTCF).

**Methods:** Data originates from the EU-funded SHELTER database, collected from 59 LTCFs, in 7 European countries, and Israel, in 2009–2011. The assessments were performed by trained nurses using interRAI-LTCF form ([www.interRAI.org](http://www.interRAI.org)). Multiple X<sup>2</sup> -tests, and logistic regression analyses were performed to find out the independent predictors of TF.

**Results:** Of the 4156 LTCF residents, 701 individuals were 65 years or older and filled the criteria for end stage dementia: diagnosis of dementia, severe cognitive impairment (Cognitive Performance Scale 5–6), and dependent or fully dependent in ADLs (ADL hierarchy Scale 5–6). Mean age of these residents was 86,1 years (65–110), and 80,7 % were female. Forty eight residents had either nasogastric tube or PEG (6.9 %). In three countries, no tubes were found. In the logistic regression analyses, female sex (OR 3.9 95%CI 1.28–11.7), difficulties with secretions in airways (OR 3.5 95%CI 1.64–7.62), afasia (OR 2.9 95% CI 1.41–6.06) sleepiness (OR 2.6 95%CI 1.38–4.93), and diagnosis of stroke (OR 2.3 95% CI 1.17–4.43) were the independent predictors for TF. Of the care procedures only number of physician's visits (OR 2.5, 95%CI 1.12–5.45) and positioning/turning program (OR 8.3 95% CI 3.34–20.1) were significant, when country of residence had been taken into account.

**Conclusion / Discussion:** Tube-feeding seems not be prevalent, in end stage dementia, in Europe. However local differences may exist.

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## Self-management Support Interventions for Informal Caregivers of People with Dementia: A Systematic Meta Review

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**Background:** Dementia is a life-threatening disease, requiring a palliative care approach where supporting informal caregivers in managing the symptoms and problems related to the dementia should be part of. However, it is not clear which self-management support interventions are most effective.

**Aims:** To synthesise evidence from previous systematic reviews on self-management support interventions for informal caregivers of persons with dementia.

**Methods:** This systematic meta-review followed the PRISMA Statement. Searches were conducted in Pubmed, CINAHL, Cochrane Library, Embase and PsycINFO. A two-step selection was performed:

- (1) screening based on titles/abstracts and
- (2) screening based on full-text. Methodological quality was assessed by the Quality Assessment Checklist for reviews. Interventions were grouped using an earlier developed categorisation of self-management, covering 5 intervention targets:
  - (1) relationship with family,
  - (2) maintaining an active lifestyle,
  - (3) psychological wellbeing,
  - (4) techniques to cope with memory changes and
  - (5) information about dementia.

**Results:** 10 systematic reviews were included. Strong evidence exists for self-management support interventions focusing on family relationship in relieving caregiver burden. There is moderate evidence that self-management support interventions targeting psychological wellbeing contribute to a reduction of depressive symptoms. Last, strong evidence was found that interventions targeting 'information about dementia' increase well-being, and moderate evidence was found for a decrease of depression.

**Conclusion:** This meta-review indicates that self-management support interventions by health care professionals have positive effects on various outcomes of informal caregivers of people with dementia.

**Funding:** The Netherlands Organization for Health Research and Development (ZonMw).

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**Abstract type:** Poster

## Mapping Palliative Care Provision in Long Term Care Facilities for Older People in Europe: Outcomes of the EAPC Task Force

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**Background:** Older people are increasingly dying in long term care facilities (LTCFs) due to ageing populations and growth in non-cancer diseases and dementia. Palliative care (PC) is well organised in many countries and provision diverse, but PC in LTCFs is a recent development. *Comparing the effectiveness of Palliative Care for Elderly people in LTCFs in Europe*

(PACE) is an international study on the state of current provision.

**Aims:** To map provision of PC in LTCFs in Europe.

**Methods:** Extending an earlier LTCF EAPC Taskforce from 13 to 29 countries, a mapping survey was sent to key country informants from PC, long term and geriatric care settings between April and August 2014. LTCF demographic data, PC activities and current practices are classified and key common components identified. Data were analysed using a coding template for LTCF funding and organisation, resident populations, regulation and training, and PC practices and innovative approaches to provision.

**Results:** Data show differing PC provision for 23/29 countries. Reported initiatives illustrate cross country provision, with limited regional/organisational level initiatives in Central and Eastern European countries. Relevant national policy level PC developments are reported, with limited focus on LTCF populations.

**Conclusion:** There are challenges for LTCFs in providing PC, with complex funding, organisational partnerships, regulatory frameworks and policy directives shaping delivery and care provision. Comparisons across Europe are difficult owing to varying levels of data available by country. All countries have systems of regulation to ensure minimum standards for quality care in LTCFs. The intended focus of PC interventions or developments are often patient and family focused. Other benefits can be seen for individual staff, teams and organisations. Evidence remains limited with few rigorous evaluations of such developments.

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## Inter-disciplinary Perspectives on Palliative Care Provision for Older People: Barriers and Facilitators

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**Background:** In September 2013, the Maruzza Foundation, EAPC, and the EUGMS launched a manifesto: 'Palliative Care for Older People in the European Union'. The aim was to raise the profile of the needs of older people for palliative care and assist policy makers and organisations to improve palliative care for older people in Europe. Subsequently, a working group was established to work with key stakeholders.

**Aim:** To identify:

- (1) collaboration between palliative care and geriatric care
- (2) barriers and facilitators to on-going collaboration.

**Methods:** A descriptive exploratory study was undertaken. Four discussion groups were held: two groups at each organisation's annual conference. Analysis was undertaken using a coding template to identify key issues under pre-determined themes.

**Results:** Thirty three participants (24 women and 9 men), from 18 countries worldwide, participated. The following disciplines and backgrounds were represented: medicine, nursing, policy and research in geriatrics and gerontology, palliative care and primary care. Examples of collaboration were identified in clinical care, education, policy, research and leadership and organisational structures. Clinical collaboration often relied on the individual clinician as the driving force for the service. Barriers and facilitators identified concerned: different understandings of palliative care, funding models for care; availability of geriatric and or palliative care specialists in care settings; role of geriatricians in palliative care teams and inter-disciplinary education opportunities.

**Conclusions:** Whilst barriers to collaboration exist, examples of innovative collaborations drawing upon personal and service expertise exist across Europe.

**Abstract number:** P2-467

**Abstract type:** Poster

## Qualitative Study on the Perception of Hospice Nurses in Relation to the Palliative Sedation in Adult Cancer Patients

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**Context:** Palliative sedation (PS) is the subject of many extensive medical and ethical debates regarding end of life decisions. Nurses are important participants in the conduct and use of this practice, but despite this, only 9 articles that investigate the nursing experience in the field of palliative sedation were found in the last 10 years.

**Objective:** To explore and describe the knowledge, perceptions and experiences the nurses have within the Hospice of PS.

**Methods:** Face to face interview from the article 'Nurses' Perception of Palliative Sedation in a Scottish Hospice: An Exploratory Study' (CL Zinn et al, 2012 Jul.), a group study of 19 nurses from 7 Hospice's in Milan. All the data collected was organised and analysed through a system of categorisation of data, through the use of concept maps.

**Results:** The group interviewed, all female, average age 40 years, average length of service of 17.5 years, and in palliative care 8 years. All nurses have described PS as an indispensable and important method to accompany the terminally ill to a peaceful death with dignity, creating conditions of peace and tranquility. More than 80% of respondents did not report discomfort in the use of PS as this is seen as the end result of a process of sharing between the team, patients and caregivers. The group involved is aware that PS does not affect the survival times of patients and the practice, only when it considers it truly necessary. Respondents expressed the need of having to periodically discuss and share with the team, ethical situations more complex in order to share and resolve inner conflicts unleashed from a subject as painful as the end of life.

**Conclusions:** PS is looked at by the nurses as a fundamental practice. There is a need for more training on palliative care not only in environments such as Hospice, but also in all hospital departments to ensure a peaceful death to all terminally ill patients.

**Abstract number:** P2-468  
**Abstract type:** Poster

## How Do Older People with Incurable Cancer Experience Daily Living? A Qualitative Study in Norway

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**Background:** In Western countries, an increasing proportion of patients in specialised healthcare contexts are older people living with incurable cancer as a chronic disease, requiring palliative care for shorter or longer periods of time. The aim of our study was to describe how they experience daily living while receiving palliative care in specialised healthcare contexts.

**Method:** Qualitative research study with a phenomenological approach called 'systematic text-condensation'. Twenty-one participants, 12 men and nine women aged 70–88, were interviewed with a semi-structured guide. They were recruited from two somatic hospitals in southeastern Norway.

**Results:** The participants experienced a strong link to life in terms of four subthemes: to acknowledge the need for close relationships; to maintain activities of normal daily life; to provide space for existential meaning-making; and, to name and handle decline and loss. They also experienced that specialised healthcare contexts strengthened the link to life by providing person-centered palliative care.

**Conclusion / Discussion:** The main finding demonstrates that older people both had a wish and an ability to continue with life-oriented daily living. Though a central subtheme in itself, existential meaning-making ran as a red thread through all the subthemes, representing through very different expressions the core of what is most meaningful and valuable in life. Thus our study showed that existential meaning-making and resilience were the overarching processes for these older people. Insight into these processes are seen as useful in order to increase the understanding of how older people adapt to adversities, and how their responses may help to protect them from some of the difficulties in aging. Healthcare professionals can make use of this information in treatment planning and for the identification of psychosocial and sociocultural resources to support older people and to strengthen the persons' own life resources.

**Abstract number:** P2-469  
**Abstract type:** Poster

## Review of Nursing Home Residents Referred to the Specialist Palliative Care Service during their Inpatient Stay in an Acute Hospital Setting

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**Background:** Optimisation of quality of life for patients with advanced life-limiting illnesses is a key goal of specialist palliative care. Hospitalisations of nursing home (NH) residents can be associated with deterioration in quality of life. We reviewed the number of NH residents referred to the hospital specialist palliative medicine service (SPMS) with an established plan of care.

**Methods:** The palliative care database was used to identify all NH patients referred to the SPMS from June–September 2013. Data collected from patients' medical records included: reason for admission, source of referral, readmission within 30 days, length of admission, reason for SPMS referral and established ceiling of care. Data was analysed using Excel.

**Results:** 22 patients were available for analysis. 20 (91%) had a non-malignant diagnosis and respiratory infection was the main reason for admission in 11 (50%). No patient had a care plan documented on admission. End-of-life (EOL) care was the primary reason for referral to the SPMS in 10 (46%). 14 (63%) residents were referred to hospital by nursing staff in the NH. 9 (41%) were readmitted within a 30 days. Mean length of stay was 13 days (range 1–33). Seven (32%) referrals died in hospital, which included 4 (46%) of the 9 referrals readmitted within 30 days. Of the 15 referrals subsequently discharged back to the NH, 6 (40%) had a ceiling of care established.

**Conclusion:** Plans and ceilings of care are essential in optimising patient comfort towards EOL and may help decrease unnecessary hospital admissions. Communication regarding the discharge plan between doctors, patient/family, NH staff and GP is essential. Our service is adapting to strengthen links and provide increased support to NH staff and GPs in providing high quality EOL care in the NH setting.

**Abstract number:** P2-470  
**Abstract type:** Poster

## What Influences the Transfer of Nursing Home Residents to Emergency Departments; Good Planning, Prescribing and Primary Care Needed

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**Background:** Health and social care systems increasingly face challenges of caring for an aging, comorbid population. More deaths are occurring in nursing homes (NHs) with increasing pressure to avoid unnecessary costly hospitalisation.

**Aims:** To determine the frequency, and factors associated with, emergency department (ED) transfers of NH residents towards the end of life.

**Methods:** Secondary analysis of data from a cluster RCT of facilitation methods to implement Gold Standards Framework in Care Homes. Descriptive statistics were used to report frequency of ED transfer. Multivariable logistic regression identified factors associated with ED transfer.

**Results:** Data was extracted from records of 2,444 residents in 38 NHs over last 6 months of life. Residents were 61.4% female with median age 86 years. The median age-weighted Charlson index score was 6, with dementia the most common diagnosis. Only 22.2% had

contact with hospital outpatient services and 20.6% with community palliative care. 42% were transferred to ED for a diverse array of acute problems. Very few were definitively managed in the ED and most resulted in a hospital admission. 32% of residents had an admission in the last month of life, compared to 8.1% to 10.8% in the five months before this. Factors associated with lower odds of ED transfer include contact with an out of hours GP (OR 0.65 p<0.000) advance care plans (OR 0.64 p<0.000) and anticipatory prescribing (OR 0.708 P = 0.008). Factors associated with higher odds of ED transfer include younger age (OR 0.982 P = 0.002), males (OR 1.31 p=0.011), dementia (OR 1.291 p=0.042), heart disease (OR 1.28 p=0.016) and feeding tubes (OR 2.27 p=0.001).

**Discussion:** NH residents are at high risk of hospital admission once transferred to an ED. Health care service use increases in the last month of life. Interventions supporting the use of anticipatory prescribing and ACPs by GPs and NH staff are likely to reduce ED transfers towards the end of life.

**Abstract number:** P2-471  
**Abstract type:** Poster

## Breast Cancer Survivors Aged 60 and over Thrive with Dragonboat Paddling

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**Background:** In recent years, Breast Cancer Survivor (BCS) Dragonboat teams have organised to provide the opportunity for women diagnosed with breast cancer to engage in competitive paddling, an active upper body sport requiring training and regular off and on-the-water practice. An Internet survey was initiated which received responses from 749 women participating in BCS teams in the United States, Canada, England, Australia, New Zealand, and South Africa. Women 60–86 are 46 % of the survey respondents.

**Aims:** The goal of this study was to have the breast cancer survivors who paddle describe the personal impact of paddling as an active, upper-body aerobic activity on their lives after cancer treatment and how participation in a BCS team had affected their lives as cancer survivors.

**Methods:** BCS teams were contacted using E-mail and sent a letter explaining the research study, including a 'url' which provided access to the Informed Consent and survey document. Accepting the Informed Consent opened the 32 question Survey and created a private, individual data record. The only identifying data collected was a birth date.

**Results:** Women 60–86 reported: 99% began to dragonboat paddle after their cancer diagnosis; 89% paddle 2-times a week or more. Palliative benefits of paddling were: increased fitness 98%; feel better 92%; healthier 89%; stronger 89%; energised 88%; happier 83%. They said they would continue to paddle to: Keep physically active, 87%; Maintain a healthy lifestyle, 81%; Have the support of friends and the team, 83%.

**Conclusions:** For older women, dragonboat paddling provides an active, beneficial life style. For many it is a new opportunity to engage in a competitive Team sport. Team members of all ages support each other to deal with challenges of life after cancer, illustrating the potential of dragonboating as a beneficial support program.

**Abstract number:** P2-472  
**Abstract type:** Poster

## Comparing Circumstances of End-of-Life Care for Older People Living at Home and in a Residential Home in the Netherlands via a Mortality Follow-back Study

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**Background:** Due to the growing proportion of older people, their place of residence and place of care at the end of life is becoming increasingly important.

**Aim:** To compare circumstances of end-of-life care and transitions between care settings in the last three months of life among older people in residential homes and home settings in the Netherlands.

**Methods:** Using a nationwide representative mortality follow-back study, we identified patients of 74 participating GP practices who died non-suddenly over the age of 65 in 2011 and 2012. Patients whose longest place of residence in the last year of life had been a home setting (own home or a relative's home) or a residential home were included (n=498). Specialist nursing homes were excluded.

**Results:** Home settings and residential homes cater to different populations of older people: those in residential homes are older (87 versus 81), more likely to be female (63% versus 43%), more likely to have dementia (33% versus 13%) and less likely to have died of cancer (25% versus 54%). While there were no differences in treatment goals or communication about end-of-life care, those living in a residential home were more likely to have received palliative care from a GP than those living at home (58% versus 53%, odds ratio=2.8, 95% CI=1.4–5.1). Those living at home experienced transfers between care settings more often (odds ratio=2.8, 95% CI=1.4–5.6) as well as hospitalisation in the last three months of life (odds ratio=2.2, 95% CI=1.0–4.7), and were more likely to die in hospital (odds ratio=1.3, 95% CI=1.0–1.6) than those in a residential home.

**Conclusion:** Despite similar treatment goals, older people living at home are at risk of a lower quality of end of life and death than those living in a residential home. Measures should be taken to ensure that patients in different living situations receive appropriate end-of-life care.

**Main funding source:** EU Seventh Framework Programme (FP7/2007-2013, grant number 264697).

**Abstract number:** P2-473

**Abstract type:** Poster

## Hospice and Palliative Care in Long Term Care Settings: The Relatives' Perceptions of Sustainability

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**Background:** There is growing recognition in Europe that hospice and palliative care in long term care settings are relevant approaches for delivering good quality care for people living and dying in these institutions. Many innovative projects have been developed also in German speaking countries with high commitment during the past 15 years. Therefore it is necessary to find out factors supporting the sustainability of these projects.

**Aims:** The aim of the presented paper here is to highlight insights from the perspectives of relatives of people living and dying in long term care settings. As hospice and palliative care include the whole family as relevant care system we asked relatives, how they perceived the sustainability of these efforts.

**Methods:** A qualitative study based on a participatory approach was conducted. With support by management of long term care settings we organised four focus groups in different and thoroughly sampled nursing homes in Germany that have a long tradition of hospice and palliative care. The settings varied concerning place, provider organisation and composition of participants. Analysis of data was processed inductively on individual and interdisciplinary basis.

**Results:** From the perspective of relatives the following themes are key for sustainability of hospice and palliative care:

- 1) nursing homes as places 'inbetween' living and dying
- 2) Understanding and feeling understood in multicultural contexts
- 3) Communication culture between staff and relatives
- 4) Structural and organisational background
- 5) Conflicts of care
- 6) Grief and joy at the same time.

**Conclusion:** Based on these insights we conclude: Central aspects concerning sustainability of hospice and palliative care in long term care settings encompass the role that long term care settings play in society, the question how communication culture can be developed and the existential tension between living and dying.

The project is funded by the Robert Bosch Stiftung, Stuttgart

**Abstract number:** P2-474

**Abstract type:** Poster

## End of Life Care in Advanced Dementia – Choice or Necessity?

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**Background:** The UK National Dementia Strategy recommends that people with dementia are offered the opportunity to discuss their end of life care preferences while they retain capacity.

**Aim:** To explore the perceptions, opinions and experiences of people with early dementia and family carers of people with advanced dementia when considering future care choices.

**Method:** A qualitative methodology was used. Two workshops (WS) were held. WS1: 5 people with early dementia who retained capacity, MMSE > 19, 2 male/3 female, age 76–91 years, living at home supported by family. WS2: 5 family carers, 1 male/4 female, all children of people with advanced dementia resident in a care home. Workshops were facilitated by a researcher following a topic guide; an observer took detailed notes. Data analysis followed a grounded theory approach; themes were developed iteratively and inductively.

**Results:** WS1: Participants preferred to receive care in their own home. Two had initiated power of attorney documents and had limited discussions with family members regarding future care. None had made advance care plans, all expressed confusion as to the meaning of these documents. Responses suggested discussion about future care preferences are unlikely to occur without focussed support.

WS2: All family carers had tried to support their relative at home but reported that care home admission had been a necessity due to concerns regarding unsafe behaviours. They described feelings of 'relief' on care home placement. Experiences within care homes were mixed but all expressed concern about a perceived lack of staff training and ability to manage symptoms of advanced dementia or end of life care needs.

**Conclusion:** People with dementia while they retain capacity may be unlikely to choose or plan for support within a care home. However, despite family support, in advanced dementia placement within a care home may be a necessity due to needs that cannot be safely met in their own home.

**Abstract number:** P2-475

**Abstract type:** Poster

## Depression and Neuropsychological Functioning in Inpatient Palliative Cancer Care

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Cognitive functioning and mood disturbances have been closely linked across settings. Depressed older adults tend to present with poorer executive function than non-depressed. However, to date no research has explored this relationship in inpatient palliative cancer care. This study explores the relationship between neuropsychological (NP) functioning and depression/anxiety in patients with terminal cancer.

Participants included 55 terminally ill cancer patients and 50 community-dwelling adults (age 50–89). Subjects completed a series of NP tests and the Hospital Anxiety and Depression Scale (HADS). Standard scores across 8 NP tests were collapsed into 4 NP indices: Processing Speed (PS), Verbal Learning (VL), Executive Functioning (EF), and Verbal Fluency (VF). Statistical analyses explored the relationship between NP domains and depression and anxiety and differences by setting.

As expected, inpatients performed significantly worse on all NP domains and were more depressed than community-dwelling participants. However, while EF and VF were significantly correlated with depression in controls, there were no significant associations between NP functioning and anxiety or depression in inpatients. In a regression accounting for basic demographics, only EF was a significant predictor of depression. Results were consistent even when looking only at subjects age 65–89. Inpatients had more depression and more significant cognitive impairment than community-dwelling older adults. Levels of anxiety were equal across groups. However, the relationship typically observed in older adults between depression and EF was not observed. Possible explanations include the impact of pain management, as most inpatients were actively receiving pain medications that might impact cognition and/or mood. Similarly, we were not able to control for cancer treatment history and therefore the relationship between cognition and mood might have been altered due to treatment side effects.

**Abstract number:** P2-476

**Abstract type:** Poster

## Hospice and Palliative Care in Nursing Homes – Transfer to Hungary

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**Background:** Many residents of nursing homes suffer from multiple terminal illnesses, many suffer from dementia. As a result an expertise in hospice and palliative care is highly required on all levels.

**Aims and questions:** Hospice Austria has started a successful project to integrate hospice and palliative care to nursing homes in 2006. The main question was how to transfer this expertise to Hungary.

**Methods:** Hospice Austria presented the three key elements of the Austrian project (guidelines for quality of palliative care in nursing homes, a model organisational development process, a 36hrs curriculum in Palliative Geriatrics) to the Hungarian team of an EC funded project called Narzisse. In cooperation with the Hungarian Association of Hospice and Palliative Care and the local project team the guidelines and the organisational development process were adapted to meet the Hungarian needs. 3 train the trainer workshops introduced Hungarian professionals to this organisational development and the special curriculum.

**Results:** The cooperation shifted the attitude concerning PC in the Hungarian social sphere: 2 Hungarian model homes in Zalaegerszeg realised the integration of hospice and palliative care. They focus now on symptom therapy, consult PC providers, improved the communication with patients and relatives and created memorial ceremonies. 4 other nursing home intend to start.

Free social section in the XI. HHPA Congress with 50 participants.

Education:

Train the trainer workshops (see above)

4 National HP workshops in nursing homes and hospitals (50 participants)

2 HP courses of 40 hrs with 16 social workers from nursing homes, accredited for 3 yrs.

**Conclusions:** The Austro-Hungarian cooperation initiated a dialogue between PC and the social sphere, between nursing homes and PC providers, thus improving the care for residents, their families and supporting carers. It proved equally essential to have an advisory board with all relevant policymakers and to cultivate networking.

**Abstract number:** P2-477

**Abstract type:** Poster

## Care Home Deaths: A Comparison between Residents and Non-residents

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**Background:** The usual place of residence is the preferred place of death for the majority of persons nearing the end of life with 63% wishing to die at home and only 8% wishing to die in hospital and 1% in a care home.<sup>1</sup> The percentage of care home deaths is increasing with many admitted near the end of their life after discharge from hospital.

**Aim:** This study investigates the numbers of people dying in care homes (nursing & residential) comparing those who were residents and those who were not by age, gender, cause of death and geographical location.

**Method:** Information on deaths was extracted from ONS Mortality Data. To determine if a person dying in a care home was a resident, place of residence on death certificate was matched to ONS Communal Establishment database. If the postcode matched, it was inferred this person was a resident of a care home.

**Results:** Across England 1 in 3 care home deaths are for non-residents. They account for half (52%) of care home deaths in persons aged under 75 and a third (32%) in people aged 75 plus. London (37%) records the highest percentage of non-resident care home deaths, Yorkshire and the Humber (31%) records the lowest. Dementia is the leading cause of death among care home residents with cancer the leading cause of death among non-residents.

**Conclusion:** The population in England is ageing with people living longer and care homes are the place of death for an increasing number of people. The increase in non-resident care home deaths may reflect that more people are living alone and unable to maintain themselves at home at the end of their lives. With more people with complex conditions transferred in to a care home setting near the end of their life, care homes must be adequately resourced to enable people to die comfortably as in the Dutch model of care. Further study could examine differences between nursing and residential care homes.

**References:** 1. www.sueryder.org/~media/Files/About-us/A-Time-and-a-Place-Sue-Ryder.ashx



Abstract number: P2-478  
Abstract type: Poster

### Researching Non-kin-Care Relationships in End-of-Life care – Methodological Challenges

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**Background and aim:** The percentage of people living in a single household in western societies has increased in the last decades. Many of them have no family nearby and do have palliative care needs, e.g. frail older people. Non-kin-carers play an essential role to support these individuals' preferences for staying at home, even until death. However, non-kin-carers usually are not considered in research. In a study which aimed at getting insight into non-kin-care relationships of older people living alone at the end of life, substantial methodological and ethical challenges emerged worthwhile to be discussed.

**Method:** A qualitative design included narrative interviews in retrospect with non-kin-carers (n=15) aged between 52 and 84 years. As part of the case study approach, additional interviews with selected health professionals (n=8) were conducted. A research diary was kept and discussed throughout the study. In retrospect of this study we reflected upon methodological challenges and issues in a focus group discussion with an interdisciplinary team of researchers (n=5).

**Results:** As non-kin-care does not take place within organisations, access is difficult. People often suppose their engagement as private and some do not consider themselves as carers. An open call for participation is therefore useless. The retrospective design implied that the caring process had finished. Therefore health professionals or legal attorneys often had lost touch with the non-kin-carers, except for specialist palliative care services that provided support with bereavement. Regarding research ethics, approaching non-kin-carers is demanding, since there relationships mostly have no legal status and data protection issues prohibit research.

**Conclusion:** Research of informal caregiving in palliative care will have to go beyond families. This requires research designs with 'mixed recruitment approaches' and thorough reflection of challenges in order to enhance good quality of research.

Abstract number: P2-479  
Abstract withdrawn

## Palliative care in children and adolescents

Abstract number: P2-480  
Abstract type: Poster

### The Experience of Teenagers and Young Adults (TYAs) Having Cancer Treatment in an Adult Setting: A Systematic Review of the Literature

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**Background:** Every year, 2,200 teenagers and young adults (TYAs) aged 15–24 are diagnosed with cancer in the UK. Best practice guidelines recommend that TYAs with cancer be treated on specialist adolescent units, of which there are now 27 in the UK. These units are considered to provide clinical and psycho-social benefit to young people. However the majority of TYAs with cancer (70%) actually have their cancer treatment at their local hospital or at cancer centres along with adult patients of all ages, and do not receive the recommended age-appropriate care provided on specialist units.

**Aim:** To undertake a systematic review of the literature to discover what is known about the experience of teenagers and young adults who received any cancer treatment in an adult setting.

**Methods:** A systematic search was conducted in May 2014 of five major electronic databases: Academic Search Complete, CINAHL, PsychINFO, PubMed and Scopus. Meta-synthesis was used to integrate the results.

**Results:** Based upon strict eligibility criteria, 14 studies (4 quantitative, 9 qualitative and 1 meta-synthesis) were identified reporting primary data about the TYA experience of cancer treatment in an adult setting.

**Conclusion/ discussion:** Synthesis of the 14 papers suggests that TYAs find adult units isolating, boring, distressing and undignified. They are generally not critical of the medical/clinical care they received, but find the psycho-social care to be lacking. TYAs report that staff working in adult settings do not know how to relate to younger people and the ward routines can feel inflexible and inappropriate. They also report that adult units lack any leisure space or facilities for friends and family to stay. TYAs miss having peer contact and can find being amongst older patients distressing and can reinforce the fear of death. Findings from the majority of studies suggest that a specialist TYA unit would be the preferred place of care for TYAs with cancer.

Abstract number: P2-481  
Abstract type: Poster

### Use of Dronabinol in Children: A Cross-national Survey

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**Background:** Despite a myriad of studies and case reports in different fields of medicine documenting beneficial effects of dronabinol in adults (e.g. in multiple sclerosis), little is known about the impact of dronabinol to alleviate burdening symptoms in children. Moreover it is to date quite unclear to which extent pediatric patients have access to dronabinol.

**Methods:** We contacted 317 pediatric institutions in Germany, Switzerland and Austria (27% questionnaire return rate) using a 17 item questionnaire send via email.

**Results:** 39 out of 85 responding institutions (46%) declared dronabinol use. Most commonly treated symptoms were: spasticity, pain and loss of appetite. 87% of the respondents used daily dosages between 0.25–0.75 mg/kg/day. Again 87% of the respondents reported on clinical effects often within days after starting with dronabinol. 41% of the respondents reported about minor adverse effects (dizziness, agitation, slightly reddened eyes). Major obstacles for dronabinol use are cost coverage problems with the health insurance and a general lack of information concerning indications and dosages for children.

**Conclusions:** A substantial number of pediatric institutions use dronabinol to treat various symptoms in children. The vast majority report about clinically relevant effects. Nevertheless there are many uncertainties with respect to indications, dosing and cost coverage. Clinical trials helping to establish dosage regimens for children would be as essential as trials focussing on specific indications.

Abstract number: P2-482  
Abstract type: Poster

### Pediatric End-of-Life Care in the Home Care Setting: Creating and Balancing Family's Lifeworld

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**Aims:** This study explored the parental experiences and needs during their child's end-of-life (EOL) care in the home care setting. The patient's characteristics, and current provision were described, and influencing system factors for the EOL care were determined.

**Background:** Parents experiencing their child's end-of-life care at home face a most existential and challenging time. Their experiences/needs are influenced by system factors on different system levels (national, health care, family, and individual levels). Little is known about parent's experiences/needs and the influencing system factors for child's EOL care at home.

**Methods:** This substudy of the nationwide survey 'Paediatric End-of-Life Care Needs in Switzerland' used a concurrent qualitative embedded mixed methods design. It included 46 families, whose child (0–18y) died in the years 2011–2012. Ten parents were included in semi-structured interviews, analysed by 'thematic analysis'. Patient's characteristics were obtained from patient's medical charts and parental experiences/needs through the parental questionnaire (n=65). Appropriate descriptive statistics and logistic regressions with generalised estimation equations were computed.

**Results:** Parents expended enormous effort by creating a family's unique lifeworld, and balancing it with the challenges of the outside world during child's EOL care at home. They were supported in child's EOL care by professionals (community care 50%, clinicians 50%, pediatric palliative care (PPC) teams 28%). Influencing factors for child's EOL care at home were found to be the parental 'readiness', child's diagnosis, and sociodemographic factors. The access to EOL services correlated with proximity to the treating center.

**Discussion:** Individual-tailored EOL care with flexible approach (eg. a hospital-based PPC team), is needed in order to fulfil the needs of the child and family. Practical help in house holding was a major need of mothers.

**Abstract number:** P2-483

**Abstract type:** Poster

## Specialized Paediatric Palliative Home Care in Germany – Different Models of Service Provision

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**Background and aims:** Since 2007, the children's right to specialised paediatric palliative home care (SPPHC) became law in Germany. According to estimates, a nationwide comprehensive SPPHC is possible by the implementation of about 30 regional teams. To date, 25 of these teams exist within the country. Their design differs depending on regional geography, healthcare structures and resources. The aim of our study was to compare different SPPHC teams in terms of formation and service provision.

**Methods:** Examination of 3 different SPPHC teams concerning their structure, regional conditions, and characteristics of service provision in 2012 and 2013. The documentation of SPPHC was conducted using a similar online data base.

**Results:**

**Regional geography:**

- 1) Territorial State;
- 2) City state;
- 3) Densely populated area.

**Team structure:**

- 1) 5 regional specialist teams with a common central office providing coordination and administration.
- 2) Central specialist team providing medical and nursing home care, coordination and administration, supported by 2 paediatric home nursing teams and 4 specialised physicians from surrounding hospitals;
- 3) Regional specialist team based at an oncology department of university clinic.

**Catchment area:**

- 1) 48.000 km<sup>2</sup>;
- 2) 1200 km<sup>2</sup>;
- 3) 5.000 km<sup>2</sup>

**Start of service provision:**

- 1) 4/2010;
- 2) 05/2011;
- 3) 1/2010.

**Number of patients (2012 + 2013):**

- 1) 60 + 66;
- 2) 50 + 63;
- 3) 37 + 42.

**Conclusion:** Different regional models were implemented to comply with the legal right to SPPHC in Germany. Their design depends on regional conditions.

**Abstract number:** P2-485

**Abstract type:** Poster

## Bridging the Gap for Young People in Transition between Children'S and Adults Services

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**Aims:** A UK wide *Transition Taskforce* was established to lead a coordinated strategic approach to providing and developing care and multi-agency support for young people with life-limiting conditions making the transition to adulthood.

**Approach:** Former activity relating to the transition between children's and adult services has tended to focus on the 'push' from children's services and the Taskforce is now working with adult services to support them to match this with a 'pull' to ensure that young people make a successful transition to adult care and are able to live as independently as they wish and achieve their aspirations. The Taskforce works at 4 levels in order to achieve its aims: Nationally, to coordinate the overall work, develop materials, share information, create national collaborations and links, and to oversee the development of regional action groups; Regionally, through Regional Action Groups, to identify needs in their area, promote regional collaboration and identify organisations that can promote the development of services;

Locally, to develop collaboration between organisations that will lead to the provision of facilities and services to support individuals; and, Individually, to work with young people to listen to their views and to ensure that young-person centred approaches are used.

**Results:** Regional Action Groups are established in six regions of England and in Scotland, Wales and Northern Ireland. Evaluation of the project has so far highlighted four areas where further focus is needed: Opportunities for young people to gain employment; Collaboration between health, social care and education providers; Adapting existing environments to accommodate the needs of young people; Communication within and between teams.

**Conclusion:** This whole systems approach to improving outcomes for young adults in transition to adult services is a powerful and effective method, worthy of consideration in other countries.

**Abstract number:** P2-486

**Abstract type:** Poster

## Development and Validation of the APCA African Children's Palliative Outcome Scale (C-POS)

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**Background:** Assessing the outcomes of palliative care in children has been hampered by the lack of outcome measures. Thus an outcome tool was developed for use in children for clinical practice, audit & research.

**Aim:** To develop & validate the APCA African Children's POS in sub-Saharan Africa, utilising a collaborative approach.

**Method:** A literature review was conducted & the tool developed in 3 phases:

- (1) development & piloting of an initial tool in 4 sites across 3 countries (Kenya, Ug & SA) utilising both quantitative & qualitative data collection.
- (2) Revision of tool & assessment of its utility, including acceptability in practice, feasibility & face validity. 198 children recruited across Ug, Kenya, SA & Zimbabwe. Qualitative interviews were also held.
- (3) Revision & validation of the C-POS, establishing face, content & construct validity, reliability & acceptability. 302 children recruited (Ug, Kenya & SA) & 61 in-depth & cognitive interviews conducted.

The tool was finalised in September 2014.

**Results:** The C-POS is a multi-dimensional outcome tool with 14 questions, 9 aimed at the child (completed by child or proxy) & 5 at their carer. In the final validation phase, mean age for child respondents was 12 (SD= 4.9). Cronbach's alpha was 0.38 (child) & 0.56 (proxy) indicating expected moderate internal consistency. For construct validity (C-POS-PedQL) Kendall's coefficient of concordance were low-moderate as expected (0.41–0.51). Good test-retest reliability was seen with high correlation Kendall's coefficient for all items (0.67–0.88). Median time to complete at final visit was 5 mins (child), 10 mins (proxy) & 13 mins (child & proxy). Responsiveness to change was seen & interviews showed POS items mapped well onto identified needs with good interpretation (n=61).

**Conclusion:** The APCA African C-POS is a valid & reliable tool & its development is an important step forward in the measurement of outcomes in children's palliative care.

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## Creativity Required – Apply within Evaluation in a Children's Hospice

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Recent evaluations of arts projects at a children's hospice indicate that activities developed in-house by experienced specialists and practitioners are often more attuned to the needs and aspirations of children and young people (cyp) with life limiting conditions and their siblings than those led by visiting companies. This paper explores the application and evaluation process of a theoretical model 'PREPARE' (Stige and Aaro, 2012) to design, implement and evaluate activities in this setting.

**The model:** The PREPARE model, founded on the work of community music therapy practitioners, is based on seven principles:

Encouraging **participation** and inclusion, **Ecological**-based on existing relationships, Promotes **performance** as an approach to development, Is **activist** – addressing problems and influencing change, Is **reflective** through evaluation, **Ethical** – responsive and responsible.

**Method:** The model is used as a template for discussion and enables the aims and expected outcomes to meet the needs, abilities and development opportunities of life-limited children and young people. The PREPARE principles, embedded throughout the project and are driven by the interest, skills and aspirations of cyp. This was used with an arts project in a children's hospice, initiated by a young person, designed and developed by the other cyp in the hospice and produced with support from an artist, staff and volunteers.

**Results:** Young people, some with profound disabilities, through full participation produced pieces of art, sculpture, animated stories and short animated film. They saw change through increased confidence and skills, uncovered hidden talents and were rewarded by the positive response to their art exhibition held in a prestigious venue and subsequently at an international conference in Canada.

**Conclusion:** Using this model provides a systematic approach to creative activities in the hospice setting and ensures maximum empowerment and benefit for all those who take part.

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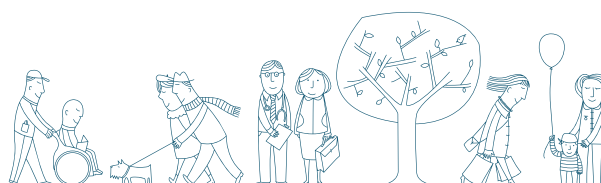
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